

# The future of HIV services in England

## Shaping the response to changing needs

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# Key messages

- More people than ever before are living with HIV in England. Although today's medicines make HIV manageable, it continues to have a major impact on people's lives. The number of people living with HIV, and living longer, will carry on increasing due to continuing incidence and highly effective treatment.
- HIV-associated stigma remains a significant factor in people's experience of living with HIV, and inhibits testing and prevention interventions.
- England's HIV services have a track record of clinical outcomes that is among the best in the world. People living with HIV can now have the same life expectancy as anyone else if treatment starts early. Services in the future must be designed to reflect the very long-term nature of HIV care.
- HIV affects a diverse range of people with very different needs. Indicators of good HIV care in the future should not be limited to how well the virus is suppressed, although that remains essential. Good care for people with HIV should go beyond this and include access to a range of support, such as peer support, which is tailored to different needs, promotes a good quality of life and freedom from stigma, and helps people control their own care.
- As people with HIV live into older age, they are likely to develop additional long-term medical problems (co-morbidities). Services that originally tackled acute infections associated with profound immunosuppression now also need to provide long-term condition management in partnership with GPs, care homes and others. The demographic shift is already visible, and HIV services need to become part of today's wider approaches to caring for people with long-term conditions.
- The Health and Social Care Act 2012 created a fragmented and complex system, which makes it more difficult to ensure a co-ordinated process of change across HIV services in response to changing needs. The reforms have made it harder to deliver integrated HIV care in the way that will be needed in future, and to progress areas needing concerted effort (such as HIV prevention and action



to reduce stigma). So far, the division of responsibilities has not impacted on the clinical quality of HIV care, but it will do so if, as appears to be happening, it creates obstacles that reduce the ability of services to adapt in line with changing needs. Unilateral commissioning decisions and financial pressures are compounding this risk for non-clinical services, such as HIV support organisations and HIV prevention.

- For HIV services to keep pace with changing needs there is an urgent need for stronger system leadership to overcome this fragmentation and complexity. Effective system leadership would draw together providers, commissioners and those people most affected by HIV as partners in an overarching plan for each area, with authority to take the plan forward across both NHS and local authority responsibilities. Directors of public health and lead HIV consultants should work together to make sure that the right leadership, structures and governance are in place for each area's needs.
- Local plans should be based on integrating services along fragmented HIV pathways and co-ordinating care around the individual. There are parallels here with approaches developed for other long-term conditions, with potential to adapt existing frameworks for co-ordinating services. They should be developed within the broader framework of sustainability and transformation plans (STPs) and health and wellbeing strategies.
- While the incidence of HIV has fallen overall, national data shows that it is still increasing among gay and bisexual men. This underlines the need for a continued future focus on prevention. NHS England, with Public Health England, needs to expedite work to understand the most effective use of pre-exposure prophylaxis (PrEP), and progress quickly from an implementation trial to a full implementation plan. No single approach on its own is a 'silver bullet' to stop the spread of HIV; there is a need for combined prevention approaches, including influencing behaviour and knowledge and expanding HIV testing.
- There are wide inequalities in rates of late diagnosis, which is associated with complex needs and poor health outcomes. Recent improvements in detecting HIV through increases in testing are encouraging and need to go further to address this.



- London faces the same challenges as other areas, but they are magnified in scale and complexity. Our recommendations for the capital city are the same as for other areas. However, there is an urgent need to get on top of London's challenges, given that nearly half of the people living with HIV in England access services there and the city has the highest rate of new diagnoses.
- National bodies have become too hands-off in their oversight of HIV services. Although these services must be developed locally to fit with different needs and experiences in each area, national bodies have essential roles in setting the overall direction, ensuring accountability and supporting the development of new care models and good practice. National leadership is also fundamental to the fight against stigma, and the NHS ought to be leading the way as an exemplar of zero stigma.

# Summary of recommendations

## Local services

- Directors of public health and lead HIV clinicians should work together to ensure effective system leadership that will get all key stakeholders on board with a single, overarching plan for developing future HIV services across the HIV pathway.
- The plan does not need to involve producing lengthy text. It should establish a shared understanding of how roles fit together to respond to changing care and prevention needs, governance across these roles, and relationships and ways of working that connect the currently fragmented system. It should focus on quality of life, including access to social support.
- Local HIV services should further develop relationships with other services for people with long-term conditions (cancer services, for example) to support common approaches and enable mutual learning.
- Local services need to test and develop future models for long-term HIV care, building on the work of pioneering services that have already started developing shared care. These models will not be 'one size fits all', but must be locally appropriate to reflect differing needs and circumstances.

## National bodies

- The Department of Health should:
  - update and strengthen the framework for sexual health improvement, reflecting the changing nature and challenges of preventing and living well with HIV in England in the 21st century, as well as providing an overall strategic direction
  - together with NHS England, lead action to reduce and eradicate stigma associated with HIV and increase public understanding



- ensure that there are clear expectations and appropriate indicators of progress for HIV prevention and care, with stronger arrangements for monitoring and accountability than at present
  - ensure that the respective roles of the Department, NHS England and Public Health England in relation to HIV are clear.
- NHS England should:
  - lead an inclusive process to decide the service models that it will commission in the future and how they fit with services commissioned by others
  - ensure that HIV services are engaged in the broader direction of travel for health services, especially care for people with long-term conditions, and are engaged in STPs
  - encourage and support the NHS to be the best it can in delivering high-quality, effective HIV treatment, care and prevention, including by making the NHS an exemplar of zero stigma.
- Public Health England should:
  - provide leadership to prioritise sexual health promotion and HIV prevention, building on the opportunities of increased testing, early initiation of anti-retroviral therapy (ART) and emerging indications of the impact of PrEP, so as to ensure combined approaches that include behavioural strategies as well as biomedical ones
  - continue to provide high-quality national and local information on HIV, and build on this through a wider range of indicators and greater clarity about how public health data leads to decisions on local action, especially in reducing variation in rates of late diagnosis.
- Health Education England should:
  - engage with HIV services through its regional offices, and ensure that workforce implications, development needs and opportunities for innovation across the local system are identified and fully reflected in commissioning decisions.





# 1 About this research

Our research aimed to make recommendations to those responsible at local and national levels for planning and delivering HIV services on how best to develop those services over the next 5–10 years.

It included a review of existing literature and data, and interviews with national stakeholders. We then looked in detail at four geographical areas as case studies of how HIV services currently operate and the issues they face. This included finding out about patients' experiences, through focus groups and interviews with people living with HIV. We held five focus groups and interviewed around 100 individuals, including direct input from 38 people living with HIV. Through the project's advisory group and membership of our research team, we involved people living with HIV in all aspects of the study.

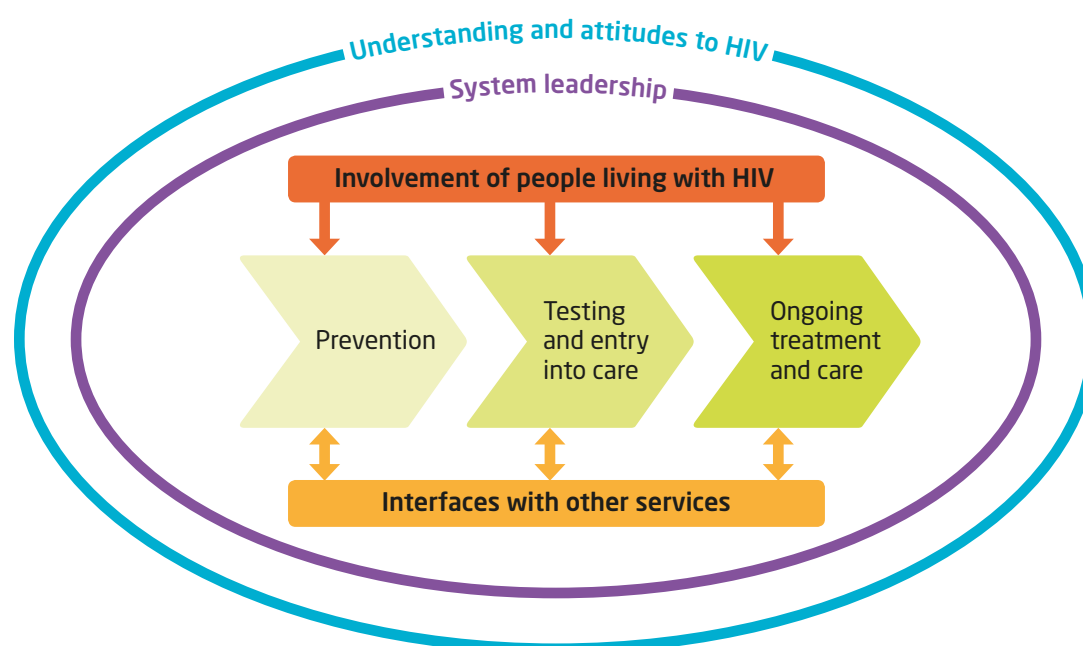
We selected case study areas to give a diverse range of settings, including urban and rural areas, areas with high and low HIV prevalence, and a wide geographical spread (north and south of the country, and London). In London we sampled different roles and functions from the city as a complex system, whereas in other areas we looked across all aspects of one service. Their characteristics are summarised in the section on findings (*see p 19*), and our research methodology is described fully in Appendix B.

The scope of our research covered a broad definition of HIV services (illustrated in Figure 1), which comprised:

- HIV prevention services
- HIV testing
- HIV treatment and care
- interfaces between HIV treatment and care and other services such as primary care
- commissioning of all of the above

- how people living with HIV are involved in shaping local services
- attitudes towards, and understanding of, HIV
- system leadership to co-ordinate and steer activity on all of the above.

**Figure 1 Scope of HIV services**



In this report, we first describe the context for our research and the recent developments that make it important to look at HIV services now and for the future. We then present findings from our case studies and the issues they raise. We reflect on the implications for other HIV services of our findings in London, and the implications for other sectors of our findings about HIV. In the final section, we present recommendations for the actions needed to deliver and develop HIV services in England over the next 5–10 years.

This research was funded by a grant from the M·A·C AIDS Fund. It was carried out independently and the findings are The King's Fund's alone. We are grateful to the M·A·C AIDS Fund for its support.



## 2 Context

England has an outstanding record of achievements in HIV prevention, treatment and care. It performs well on targets set by UNAIDS (the specialised agency of the United Nations to combat the global HIV epidemic), and achieves clinical and virological outcomes of care that are among the best in the world (Kirwan *et al* 2016). But today, HIV services in England are at a transition point. In this section, we set out the challenging context, which is characterised by the following.

- **Changing needs:** Effective treatments mean that increasing numbers of people with HIV now have normal life expectancy. As a result, we are seeing rapid increases in both the overall number of people and the number of older people living for long periods with HIV alongside co-morbidities such as hepatitis and mental health needs, plus health and care needs associated with ageing. Are services prepared for larger numbers of people with HIV, with needs that are different from those in the past?
- **Changing roles and responsibilities:** Previously, all HIV services were commissioned within the NHS, either via local primary care trusts (PCTs) or through specialist commissioning. But the health reforms of 2012, implemented from 2013 onwards, divided up responsibilities for HIV and for sexual health between NHS England, local authorities and clinical commissioning groups (CCGs). How are HIV services managing this complex arrangement? Can they keep pace with changes to HIV services that will be needed in the future, and with new technologies and interventions?
- **A changing policy environment:** Health policy overall is encouraging integration and new care models to ensure sustainable services. How will these broader changes affect HIV services, and what opportunities do they create?

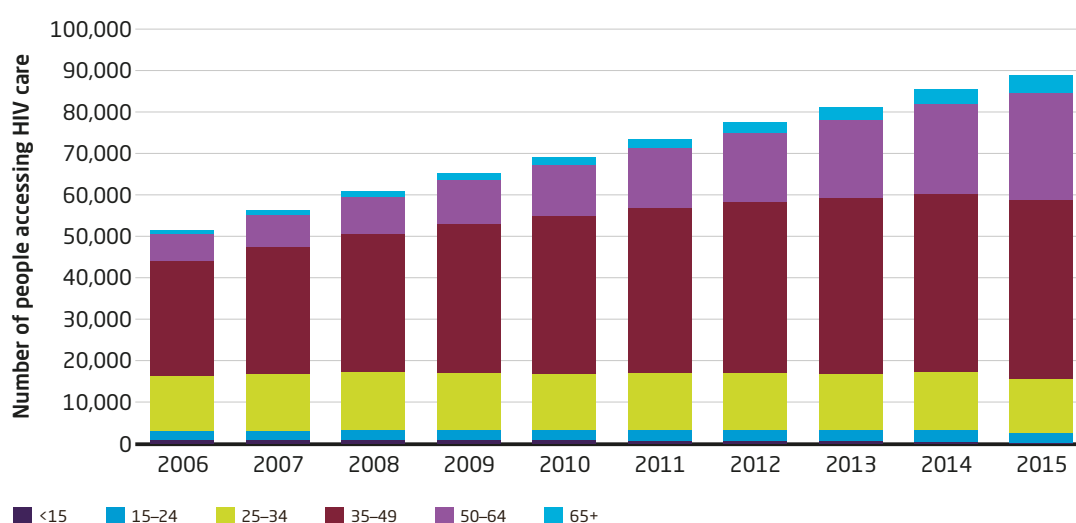


## Long-term care for people living with HIV

The most recent estimates are that 101,200 people live with HIV in the UK, of whom 13,500 are unaware of their infection (Kirwan *et al* 2016). For people who are diagnosed early and who have consistent antiretroviral (ARV) therapy, HIV can be clinically controlled for the long term. Because HIV was only first recorded in the 1980s, long-term care for people living with HIV is still a new phenomenon, with no prior body of knowledge to draw on. Services are developing in real time as the first cohort of people with HIV is growing older. HIV particularly affects a number of key population groups, compounding other difficulties that they may face (*see box below*).

The number of older people with HIV is increasing rapidly because effective treatment enables them to stay well, and because of an increase in people newly diagnosed at an older age. Currently, around one in three people (30 per cent) living with HIV in England is aged 50 or over (Kirwan *et al* 2016, *see* Figure 2). By 2028, that proportion is projected to rise to more than half (54 per cent) (Yin *et al* 2015). As people grow older with HIV, they are likely to develop other medical conditions associated with ageing (such as hypertension or osteoporosis). Some of these conditions are exacerbated by HIV and its treatment.

**Figure 2** Number of people accessing HIV specialist care, United Kingdom, 2006–2015, by age



Source: Kirwan *et al* 2016



## Key populations

The burden of HIV falls on some groups disproportionately. Each of these groups has different needs, and key populations change over time.

### Gay and bisexual men

In 2015, an estimated 47,000 men who have sex with men ('gay and bisexual men') were living with HIV in the UK. The number of new diagnoses remains high (2,800 in 2015) – accounting for nearly half of all new HIV diagnoses. Patterns of risk are dynamic with new trends emerging, high rates of bacterial sexually transmitted infections, and evidence of changing attitudes to risk-taking (Kirwan *et al* 2016).

### Black African communities

In 2015, approximately 25,600 people of black African backgrounds were living with HIV in the UK. Patterns of HIV and who it affects within this population are complex; there is no single African identity and there are diverse cultures, languages, experiences and migration history. In addition to a high prevalence and incidence of HIV, black Africans are more likely to present to clinical care with undiagnosed and late diagnosed infection than the white population (Kirwan *et al* 2016).

### Women

Nearly 30,000 women are living with HIV in the UK. A mix of biological, social and cultural factors make women especially vulnerable to HIV acquisition. Women with HIV are at greater risk of poor mental health and face greater socioeconomic challenges than men. Childbearing remains a complex issue for women with HIV.

### Migrants

Migrants living with HIV may carry a doubly compromised social identity, affected by immigration status and sometimes racism or xenophobia, in addition to the need to cope with HIV. They can face extreme social and financial exclusion and risk of exploitation (Stuart 2013).

### People who use drugs

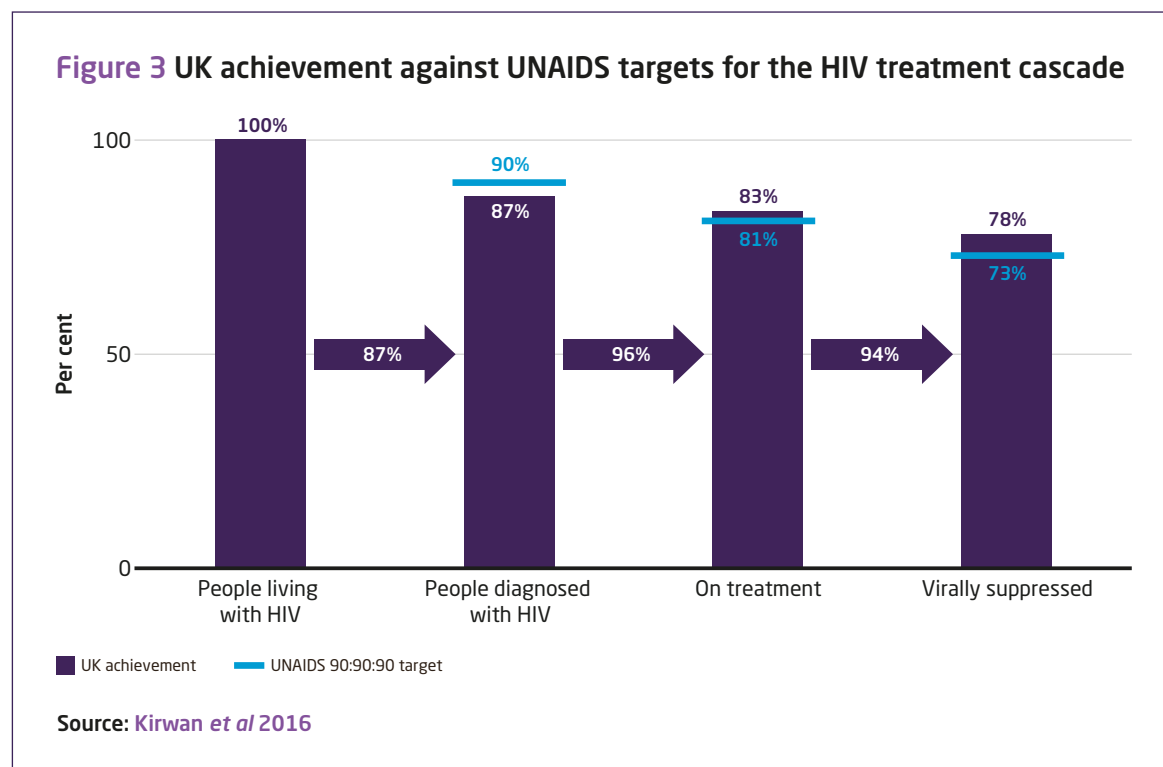
Although the prevalence is relatively low (approximately 2,500 people in 2015), HIV associated with injected drug use remains a challenge. Changing patterns of recreational drug use, particularly in a sexualised context ('chemsex'), are increasingly linked to transmission and acquisition of HIV infection.



With the development of effective ARV drugs that both preserve life and reduce infectiousness, suppressing viral activity has been a key marker of success for clinical services. UNAIDS has set targets for HIV treatment and care, presented as a treatment ‘cascade’, which reflects this. Its modelling suggests that the epidemic can be reduced if:

- 90 per cent of people with HIV have a diagnosis so that they know their HIV status
- 90 per cent of the 90 per cent diagnosed HIV-positive receive ART (ie, 81 per cent of the total with diagnosed or undiagnosed HIV)
- 90 per cent of people receiving ART achieve viral suppression (ie, 73 per cent of the total with diagnosed or undiagnosed HIV).

The UK exceeds the targets for access to treatment and viral suppression, but is not yet achieving the target for diagnosis (*see* Figure 3). The most recent national data (up to 2015) estimated that 13,500 people in the UK had undiagnosed HIV and so were most likely unaware of their HIV status ([Kirwan \*et al\* 2016](#)). Of these,





5,800 were gay and bisexual men, and even though this is a relatively small number, it was sufficient that, unlike all other population groups, the incidence of HIV among gay and bisexual men had not decreased but had continued to increase year on year.

As people live with HIV long term, a focus on viral suppression alone is not enough. There is an increased emphasis on the wellbeing and quality of life of people with HIV ([Terrence Higgins Trust 2017](#); Lazarus *et al* 2016). Certain principles have become increasingly well established within services for people with long-term conditions – principles that are equally important for people living with HIV. They include: promoting independence and economic and social (as well as clinical) wellbeing; empowering people to self-manage and make decisions about their own care; co-ordination of care across more than one long-term condition; and promoting health rather than just responding to ill-health ([NHS England 2016d](#); [Coulter \*et al\* 2013](#)).

These principles have been understood and promoted for many years in the history of HIV activism and advocacy. However, the discourse has tended to be separate to that for other long-term conditions. Care for people with HIV has various features that make it different to treating people with other long-term conditions, so approaches developed for those other conditions cannot simply be ‘imported’. Long-term HIV care is a relatively new phenomenon, and many GPs and health care professionals have low levels of knowledge and familiarity with HIV, which has historically been treated entirely within specialist clinics. Unlike HIV, most long-term conditions are not communicable diseases. HIV affects a particularly diverse range of population groups and in different ways, in terms of the risks of acquiring it and the experience of living with it. Finally, HIV is associated with a unique stigma (*see box*) ([Stigma survey UK 2015](#)).

In this research, we examined the extent to which services are prepared to respond to the changing demography of the population of people living with HIV and their changing needs.



## Stigma

Stigma has a significant impact on the physical and mental wellbeing of people living with HIV. Experiences of discrimination are common, and stigma is linked to lower adherence to treatment and worse treatment outcomes. HIV prevention is also dramatically hindered by stigma: studies have linked it to increased risk, non-disclosure and avoidance of health services, including those which may prevent transmission of HIV.

Experiences of stigma are also linked to fear and avoidance of HIV testing, so it plays an important role in driving the epidemic. People with HIV often face multiple, simultaneous layers of stigma – for example, linked to sexual orientation, ethnicity or mental health – as well as the stigma of HIV. They may also internalise stigmatising beliefs about HIV and people who acquire HIV, resulting in feelings of guilt, shame and silence. These experiences are similarly linked to a negative impact on both mental wellbeing and the ability to realise care objectives.

## The impact of the 2012 reforms

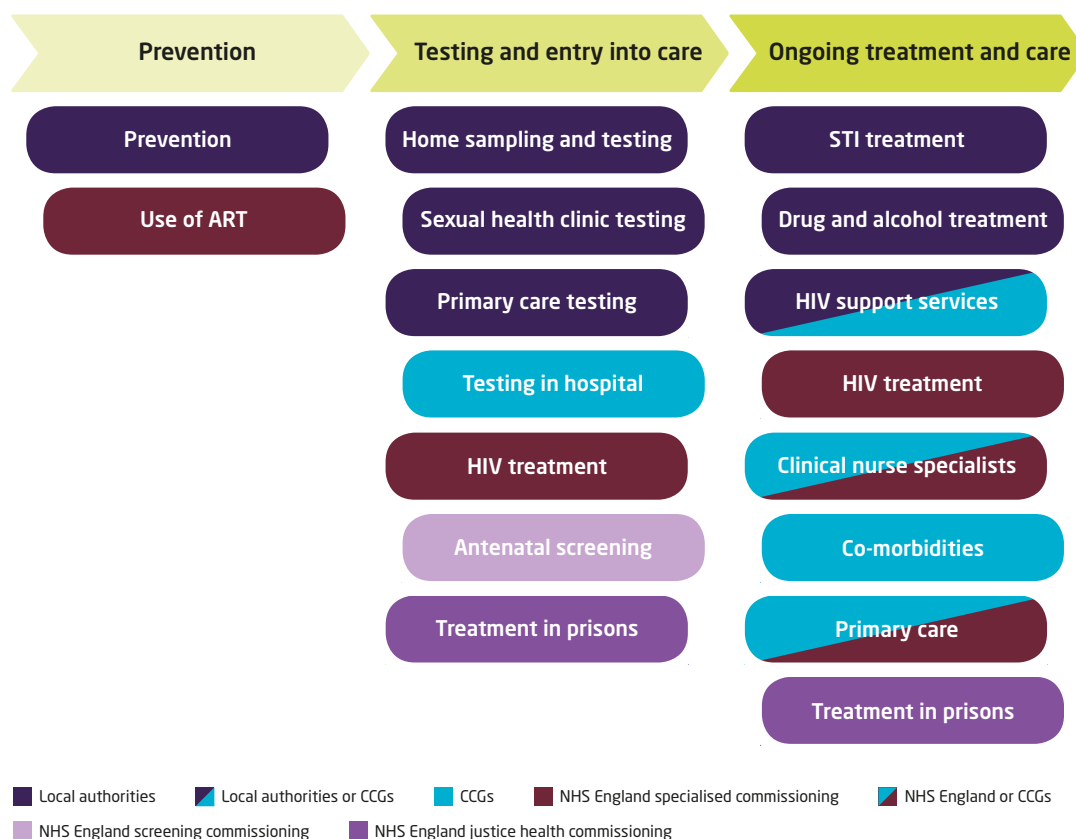
In the 1980s and early 1990s, when clinicians were still discovering how to treat and prevent HIV, services were provided entirely within highly specialised centres and funded separately to the rest of the NHS. Towards the end of the 1990s, commissioning responsibilities were devolved from the centre to PCTs.

The Health and Social Care Act 2012 created a new and complex model for the commissioning and provision of HIV prevention and care. On 1 April 2013, the landscape for sexual health services in England was transformed, when the 2012 reforms split responsibilities for commissioning across the HIV care pathway (see Figure 4 below).

Now NHS England is responsible for commissioning HIV treatment to a national service specification through its specialised commissioning programme. Local authorities are responsible for HIV testing and prevention as part of their public health functions. Local authorities are also responsible for commissioning broader sexual health services to prevent, diagnose and treat sexually transmitted infections (STIs). CCGs are responsible for HIV testing and diagnosis within other treatment episodes that they fund. They are also responsible for commissioning the treatment of most other co-morbidities (such as hypertension) that are experienced by people



**Figure 4 Commissioning landscape for HIV services since the 2012 reforms**



living with HIV. This includes knowledge and experience of commissioning services for a wide range of long-term conditions. Increasingly, CCGs also commission primary medical care, although most continues to be commissioned by NHS England area teams.

There are separate specialised commissioning arrangements within NHS England for HIV services in prisons (an important setting for HIV care) and for HIV testing as part of antenatal screening.

Responsibility for commissioning some other HIV services is not set out in law, so is discretionary and for local determination. A particular case in point is HIV support services such as peer support and counselling, which are recognised as playing an important role in HIV treatment and care – not least to support ongoing adherence



to long-term ART programmes ([National AIDS Trust 2017a](#); [NHS England 2013](#)). These services are generally commissioned by local authorities and, in a few cases, by CCGs. Arrangements for HIV clinical nurse specialists are also determined locally and are usually commissioned by CCGs ([Public Health England 2014a](#)).

Four important issues arise from this new landscape of responsibilities for HIV services.

First, various reviews and commentators have concluded that the array of different responsibilities can create fragmentation in HIV services. For example, where sexual health and HIV services have been ‘divorced’ from one another, a person with HIV and another STI may need to access two separate services. Staff may need to invest additional time and energy to co-ordinate care and share information. The All-Party Parliamentary Group (APPG) on Sexual and Reproductive Health in the UK and the APPG on HIV and AIDS have both reported on this recently and raised concerns ([APPG on HIV and AIDS 2016](#); [APPG on Sexual and Reproductive Health in the UK 2015](#)). Confusion about how the national bodies’ roles fit together and resulting gaps have also been noted, most prominently in relation to PrEP (*see box below*). The Health Committee found that the division of responsibilities results in local authorities’ public health roles having weak accountability ([Health Committee 2016](#)). We have sought to understand whether this is still the case and, if so, its impact.

Second, as the NHS and local authorities face increasing financial pressures, there is potential for disconnected strategies for dealing with reduced funding. Robertson *et al* (2017) found that although local authority commissioning of sexual health services has introduced some positive developments, it has also needed to achieve significant reductions in overall spending on sexual health in many areas, which has created risks – for example, in the level of resourcing available for prevention activity. The APPG on Sexual and Reproductive Health in the UK reported that where sexual health services are tendered without close co-ordination with NHS commissioning, and where they are not co-located with HIV services, this can result in the HIV services that are left with the NHS provider being too small to be viable ([APPG on Sexual and Reproductive Health in the UK 2015](#)). Our research considered how well plans are co-ordinated across the different responsibilities, including planning for the expected removal of the current ring-fence on local authorities’ public health budgets.



### Pre-exposure prophylaxis (PrEP)

PrEP – a way of using ART to prevent acquisition of HIV – has a strong evidence base. However, in 2016, NHS England decided that it was legally unable to fund PrEP because the legislation giving local authorities power over prevention forbade NHS England from having similar powers. Local authorities claimed (as did NHS England) that they were not allocated budgets that would enable them to fund PrEP, and that arrangements for complex medicines should be entirely under the NHS with medical oversight. The National AIDS Trust brought this impasse to a head through a judicial review. The courts found that NHS England could fund PrEP, just as it funds other preventive treatments such as statins. A research project is now looking at how PrEP might be made available on the NHS and what the implications would be.

This episode was widely commented upon for the way it illustrated the implications of the present unclear responsibilities combined with a lack of collaboration.

Third, the primacy of locally determined approaches means a weakening of the role of national bodies, which have historically been particularly strong in the HIV sector. Given the diversity of population groups affected by HIV in different areas, and the extent to which effective services are increasingly well established (without the need for close oversight that they had when very new), there are arguments in favour of locally tailored approaches rather than centrally determined ones. However, there is also a need for national oversight in preventing the spread of a potentially life-limiting communicable disease that has high treatment costs. Questions arise about what exactly the role of the national bodies should be – whether ‘hands-off’ or more actively engaged with local services.

Fourth, in contrast to the new division and distribution of responsibilities for commissioning HIV services, overall health policy has recently started to emphasise integration and pooling of responsibilities (NHS England *et al* 2014). We have sought to explore how these seemingly different directions of travel can fit together, and to identify where there are tensions between them or opportunities for further strengthening of HIV services and treatment.



## ③ Findings: HIV services today and issues they face in the future

In this section we describe our findings about HIV services and the factors that will influence the way services will develop.

For each element of HIV services (as listed in the introduction to this report), we describe:

- the context (based on the literature review and existing data)
- what our fieldwork in four geographical areas (*see* box below) adds to the knowledge base
- key implications for the future shape of HIV services.

### Our case study areas

**Case study A** – In our rural case study area, where HIV prevalence was low (<1 per 1,000 aged 15–59), specialist outpatient HIV treatment and care was provided both by sexual health physicians and infectious diseases physicians. Inpatient services were in the region's major city. A clinical nurse specialist worked across all levels of service and played an important role in ensuring that patients were supported and able to adhere to treatment. There was minimal voluntary sector or primary care involvement, and there were no HIV-specific prevention activities (they were included in sexual health promotion). Numbers of people living with HIV were too small for key populations to be identified. All services were within NHS secondary care, with the same provider also responsible for sexual health services across two local authorities.

*continued on next page*



### Our case study areas *continued*

**Case study B** – In one of our urban case studies, HIV prevalence was high (2–4.99 per 1,000 aged 15–59), with priority groups being gay and bisexual men and black African communities. Outpatient HIV treatment was provided by sexual health physicians, with infectious diseases physicians managing inpatient wards, plus two clinical nurse specialists. Primary care was becoming increasingly engaged, including a pilot scheme to increase GPs' awareness of indicator conditions and to increase the offer of HIV testing. There was significant voluntary sector provision, including contracts for targeted prevention with key population groups and support services (although the latter had been under threat of funding cuts). Sexual health services were provided by a different organisation, in premises close to the HIV clinic.

**Case study C** – In another urban case study, HIV services were delivered by sexual health physicians both in outpatient clinics and inpatient services, with clinical nurse specialists and active clinical research programmes. There was very strong voluntary sector involvement. An HIV and sexual health programme board included all statutory and voluntary organisations and some service users. A strategy had been proposed and was under consultation, with ambitious targets to reduce HIV-associated stigma, reduce new HIV infections and reduce HIV-related deaths to zero. Sexual health and HIV services were integrated within one provider. HIV prevalence was high and affected a diverse range of population groups.

**Case study D** – London had a full range of community and inpatient facilities, voluntary sector services and clinical research programmes, many of which were described as world class. A pan-London HIV prevention programme covered all the capital's 33 local authorities. There were 18 NHS trusts providing HIV treatment through 30 clinics. A transformation programme for sexual health is planned to go live in 2017. This had already resulted in the re-tendering of some sexual health services. There were plans for a significant move towards online ordering of home testing and sampling and for a reduction in the number of sexual health clinics. Reviews, re-tendering and, in some cases, closure of HIV support services were contentious. A review of clinical HIV services, which had been ongoing for a number of years, was also due to report in 2017. HIV prevalence was high or extremely high ( $\geq 5$  per 1,000 aged 15–59) in all except two boroughs and affected a complex range of population groups. Nearly half of all people in England with HIV access their care in London, including the largest number of those aged over 50.

We also talked to stakeholders in two additional areas. One of these initially contacted us to present their situation, and we contacted the other to check that we had a full range of perspectives across different levels of HIV prevalence.



## Overarching themes

In our fieldwork, we explored each element of HIV services – from prevention to ongoing care, as well as attitudes, involvement and system leadership. The findings are described in the subsections below, but three general themes emerged.

- The people we spoke to who were living with HIV placed a high value on social, psychological and emotional wellbeing, sometimes almost taking for granted the ability to manage the clinical aspects of HIV. They reinforced the importance of considering quality of life rather than just clinical or virological outcomes as a key objective for future HIV services.
- No one we spoke to, at any level or in any part of the system, thought that the distribution of responsibilities for HIV since the 2012 reforms was right. However, equally, no one wanted further distraction of energy and time through another reorganisation. They preferred to find ways of making the current, imperfect system work better.
- In thinking about the future of HIV services, many people emphasised the need to protect and build on the excellent track record in clinical outcomes, data and patient satisfaction. Particularly in this period of financial pressures, there was concern not to ‘throw the baby out with the bath water’.

## Involvement of people living with HIV

### What is the context for maximising the involvement of people living with HIV?

There is a strong history of co-production in the HIV sector, going back to the earliest days of the epidemic. Individual patients and voluntary, community and activist organisations have played prominent roles in influencing services, information, research and pharmaceutical products, and broader social attitudes, legislation and policy.

When local authorities took on responsibilities for commissioning HIV prevention services, they brought with them a strong history of involving local communities in needs assessment, planning and commissioning of services, and of promoting person-centred care. The move to make local authorities responsible for public health functions in the 2012 reforms was intended to ensure that local government



put local communities at the heart of improving health and wellbeing and reducing inequality (Department of Health 2010).

Local authorities and the NHS have mechanisms for involving people in planning local health and care services at different levels, from individual services to regional strategies. These are drawn together in joint strategic needs assessments (JSNAs) and joint health and wellbeing strategies (Department of Health 2011) and, to a lesser extent, STPs (NHS England 2016c).

### What are the findings from our fieldwork?

In the areas that we visited, we found a strong commitment to involving people in HIV services. People in our focus groups could readily give examples of being asked for their views. Providers and commissioners placed importance on involving people with HIV, in multiple ways, to ensure that the voices of diverse population groups could be heard as appropriate to the varying priorities from one area to the next.

*Yeah. It happens quite a lot. I mean, you know, people like yourselves come in and we had probably the third visit [recently] in not much more than a year. We had the council's researchers come in a year ago when they were looking at the recommissioning.*

Person living with HIV, case study area B

Examples of impact and any changes made in response to people's views or suggestions were harder to come by. In addition, almost all of the examples that we heard were about how individual services operated, rather than how the various services combined to shape people's overall experience of living with HIV. In one area, however, people with HIV were involved in the governance and oversight arrangements for HIV and sexual health services, and in developing an HIV strategy, as members of the respective programme boards and through its work streams (some of which were led by third sector user-led organisations). In our rural case study area, with small numbers of people living with HIV across a large area, there were no formal processes for people to be involved. And in all areas, we heard that people living with HIV were not all available or able to be involved, as effective treatment means that they are able to continue busy lives with little free time. Overall, we found that a consistent recognition of the importance of involving people living with HIV translated into variable practice on the ground.



*I mean, you know, we do patient satisfaction continually. It's not the same thing... actually planning changes, we don't have any patients on planning changes. Changes are to meet the financial requirements basically, or 'cost improvements' they call them.*

Provider, case study area A

Upon assuming their new responsibilities, many local authorities had carried out needs assessments. We heard of examples where these led to innovative approaches (for example, in increasing access to HIV testing) and more responsive services with better assurance of effectiveness (for example, the Do It London programme to increase HIV testing and promote sexual health). These examples were presented to us as having refreshed services that had become ossified, and refocused them more closely on what people said they needed. We also heard about other examples (for example, proposals to make HIV support services generic with support services for other health conditions) that prompted cynicism among respondents about whether they reflected what people said they wanted or were driven by financial pressures. Similarly, we heard cynicism, mainly in London, about whether and how shared care with GPs would be developed – ie, whether it would be driven by patients' views or by the need to reduce costs.

*I do know there's a plan or a programme to move everything from clinics into primary care, they move us back instead of seeing our clinics, our consultants, to see our GPs. But I would be really against that.*

Person living with HIV, case study area D

## Implications of our findings

As services and responsibilities have been distributed over more organisations since 2013, there is a risk of each organisation involving people with HIV in their bit of the picture, without anyone ensuring that people are able to influence the picture as a whole. One of our case study areas showed that this trap can be avoided; the others were all falling into it, to a greater or lesser extent.

More creativity is needed in methods for involving people living with HIV. Many people living with diagnosed HIV have incorporated it into their ongoing day-to-day lives and do not have time to be available for consultation. In rural areas, there are challenges of small numbers of people with HIV and large distances. However, HIV





services will need to change in the future, so it is essential to find ways of involving people now who may be affected by changes in future years.

Many people who are used to the current model of care may be suspicious about change. That is as true for staff as it is for patients. Those leading the development of future services locally will need to ensure full, transparent and actively offered information; they will need to give feedback so that people can see how their input is used, and they will need to be able to navigate different interests.

## Attitudes and understanding towards HIV

### What is the context for developing attitudes and understanding?

HIV is a social phenomenon as well as a clinical and epidemiological one (Mykhalovskiy and Rosengarten 2009). Stigma continues to be a major issue 36 years into the epidemic, affecting the psychological and emotional wellbeing of people living with HIV and also the effectiveness of HIV services ([National AIDS Trust 2016b](#)).

In national surveys of people living with HIV, around half of all respondents reported feelings of self-stigma. Experiences of stigma in health care settings were common: one in eight participants avoided seeking clinical care because of an expectation of being treated differently ([Stigma survey UK 2015](#)).

Available evidence shows that tackling stigma effectively requires efforts at every level, from individuals and frontline services up to government. There is a particular role for national leadership in galvanising and co-ordinating action on stigma, disseminating evidence and approaches, and leading the development of measures of progress ([National AIDS Trust 2016b](#)). However, stigma is a broad concept and is not specifically the responsibility of any one body alone.

### What are the findings from our fieldwork?

Our informants confirmed that HIV-associated stigma continues to be an important issue. Focus group participants could readily give examples, many of which were shocking and frequently occurred in health care settings. They included examples of people being required to disclose their HIV status without being able to control how the information was communicated.



*When they clicked my NHS number – you know, if you click your NHS number you get everything, everything will come out, your medical records and so forth... So when they find out that I'm HIV, that lady came to me and looked at me and said 'Oh, are you HIV?' and I said 'Yes.' She said, 'No, I don't believe it.' I said, 'Why?' 'Because of the way you look and because of the powder,' – the make-up which I'd put [on]. And she says, 'Yes, I look on you and you're not HIV.' I said, 'I am HIV positive.' So she went and told the other colleagues and they came, four of them, they looked at me.*

Person living with HIV, case study area B

Among service providers and commissioners, there was strong awareness and understanding of the impact of stigma. HIV support organisations and staff in clinics were clearly helping individuals to manage its impact, but we did not see specific programmes of work to reduce stigma more generally. Nor could we identify who, at a national level, would see themselves as responsible for reducing stigma outside of the HIV-specialist workforce of the NHS. However, one of our case study areas did have plans for reducing stigma more generally and was consulting on an overall HIV strategy that proposed setting targets towards eliminating stigma.

### Implications of our findings

Reducing HIV-associated stigma requires leadership from national bodies. Recent experience in mental health indicates that progress can be made, but it requires sustained effort and support from government as well as frontline services and community organisations (Naylor 2011).

That said, many of the examples of stigma that we heard about concerned health care settings, making the NHS an obvious priority area. If reducing stigma overall is too broad a focus to be manageable within available resources, then the NHS could provide a more tightly defined starting point, which also has management systems in place for acting on national guidance. Responsibilities for this are not obvious, but experience in the mental health sector and the leadership that has been shown for promoting parity of esteem between mental and physical health could help identify how to harness different roles and contributions.



## Prevention

### What is the context for developing prevention services?

HIV is preventable. The main types of primary prevention of HIV (to prevent acquisition in the first place) are:

- influencing knowledge and behaviour so that people avoid risks such as condomless sex or sharing injection equipment
- biomedical approaches using ART that prevent the virus becoming established.

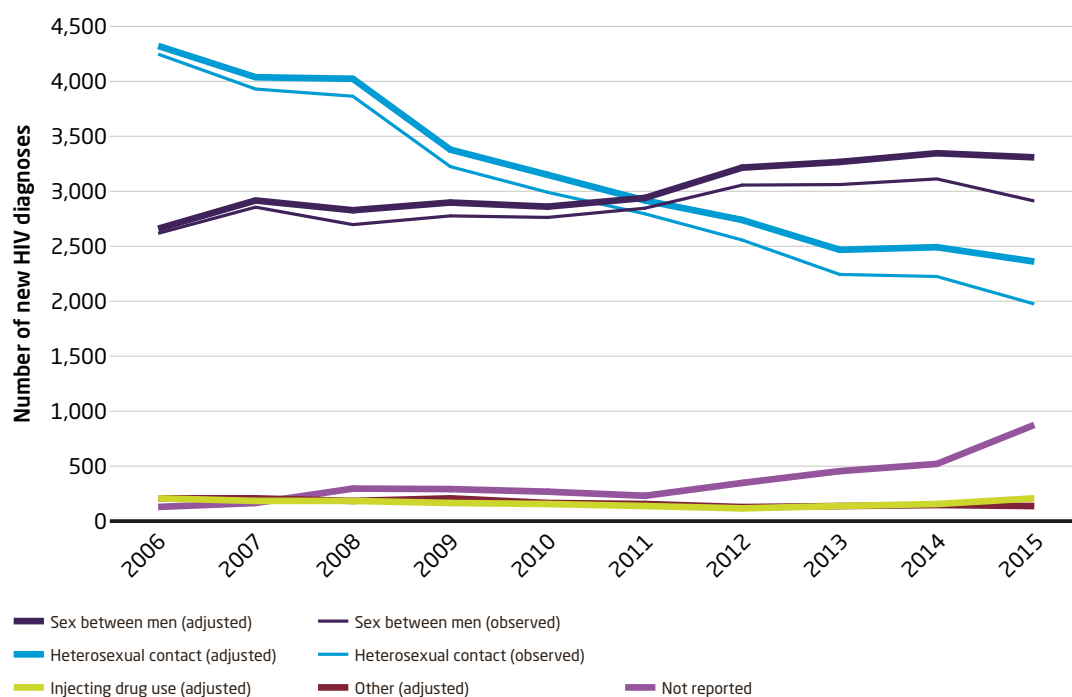
The main means of secondary prevention (to prevent onward transmission) are through use of ART to suppress viral activity, condom use and needle exchange schemes. People who are taking effective therapy and whose HIV activity is fully suppressed are not infectious to others. This means that increasing HIV testing is an essential part of secondary prevention in order to diagnose people with HIV, enabling them to access treatment and care, including ART. Regular testing is also important in primary prevention, to help people stay HIV negative.

Evidence shows that combined prevention approaches, which use all available means of prevention and tailor different interventions to different groups, are the most effective ([UNAIDS 2016](#)). For example, one modelling study suggests that using combined approaches with proven effectiveness would reduce the incidence of HIV among gay and bisexual men in the UK by 43 per cent in five years (Punyacharoensin *et al* 2015).

The most recent national data (*see* Figure 5) shows that incidence of HIV has reduced over the past 10 years among heterosexual people. But among gay and bisexual men, HIV incidence has slowly but fairly steadily increased. This underlines the need for continuing priority for HIV prevention activity.

However, very recently, a number of sexual health clinics reported large reductions in the rate of positive HIV test results – in the order of 40 per cent in some cases. The reasons for this are not yet confirmed, but the leading hypothesis is that this indicates improvements in early diagnosis (enabling treatment and thereby also preventing transmission) plus, in particular, increases in patients at these clinics using PrEP to prevent HIV ([Wilson 2017](#)). PrEP is not currently available on the NHS (*see* box on

**Figure 5 New HIV diagnoses reported by exposure group, United Kingdom, 2006–2015**



**Note:** Data was adjusted according to the distribution of exposure categories from data with information complete (86%).

**Source:** Chau *et al* 2016

p 18), but the clinics concerned had provided information to help patients safely source PrEP privately and supported them as clinically appropriate to ensure its safe use.

At a national level, Public Health England funds HIV Prevention England, which delivers nationwide targeted campaigns and supports local HIV prevention activities. Together with financial support for a home sampling service to increase testing, Public Health England funds a national HIV Prevention Innovation Fund, which awards funding to community-based organisations. Locally, responsibility for commissioning HIV prevention services in general (not limited to any particular method) sits with local authorities. However, responsibility for funding ARV medicines – used for treatment, and now also one of the key means of



HIV prevention – sits with NHS England. Confusion over which of these bodies had the legal powers and resourcing to fund PrEP following the 2012 reforms resulted in an impasse, which was not resolved until the courts decided in mid-2016 that NHS England could legally fund it. NHS England, in partnership with Public Health England, is now preparing to launch a large-scale trial over three years involving at least 10,000 people to assess the options for making PrEP available on the NHS in the long term ([NHS England 2016a](#)).

### What are the findings from our fieldwork?

Our four case study areas had very different approaches to HIV prevention. In London, there was a high-profile, city-wide prevention programme that all boroughs participated in, which focused on increasing HIV testing and awareness. In the rural case study area, there was no separate prevention programme but HIV prevention messages were included in sexual health promotion to those already in contact with services. In one urban area, third sector organisations were engaging directly with different population groups with a range of outreach activities, using different approaches for different groups. The other urban case study area was the only one in which HIV prevention could clearly be seen as part of an overall strategic approach to HIV, joined up with treatment, care and stigma reduction and aligned with sexual health and mental health strategies.

Overall, although there were active prevention programmes, there was a greater clarity of direction and of ambition for secondary prevention (especially testing) than for primary prevention. We heard about difficulties in knowing how to approach prevention in rural areas, where key groups may be different to those identified in larger populations. For example, there was relatively little national guidance and materials on how to target the group causing most concern locally (mid-life heterosexuals) at the time of our visit to the rural case study area. In cities, we heard of uncertainty about whether prevention activity was able to keep pace with fast-changing attitudes to risk and behaviours, and maintain impact.

These findings complement analysis by the National AIDS Trust ([2015](#)), which found overall inadequate funding of HIV prevention, with wide variations and no correlation between funding and HIV incidence. They are also consistent with findings from other studies, which conclude that when local systems are under financial pressure, primary prevention is particularly at risk ([Robertson et al 2017](#)).



Overall, we observed that primary prevention was a difficult proposition, was funded by local authorities under significant financial pressure, and suffered from unclear focus and commitment; whereas biomedical interventions were more straightforward, had national funding from NHS England or Public Health England, and noticeably overshadowed primary prevention.

*People have got used to it [HIV]. Because you see an HIV ad on the back of a bus, 'oh look, it's HIV – whatever.' Prevention is a hard sell. I think that selling the idea that HIV is such bad news when there are such good controlling drugs in the meantime, men being men, young men being young men... I think is a tough one.*

Person living with HIV, case study area D

We spoke to people in one area (not a case study area) with middling prevalence of HIV, but clearly on track to meet the definition of a high-prevalence area soon if current trends continue. Becoming a high-prevalence area has implications such as expectations for expanding HIV testing (for example, in primary care and other non-HIV specialist services in hospitals) (NICE 2016a). However, there were no particular plans in place to try to avoid becoming a high-prevalence area or to engage non-HIV specialist services. There was a sense that increasing prevalence was inevitable, that prevention was not a priority given the availability of effective treatments, and that HIV was 'owned' by national bodies rather than engaging local commissioners' attention.

*I don't know, I haven't seen much evidence of... I don't know how that [planning in response to increasing prevalence] would be, I'm not really sure to be honest, I don't know how that would be managed. Because we're not seeing huge epidemics, it's not really, you know, it's – yeah, numbers are going up, definitely, but, which we're aware of, but not to the sort of great extent you might see elsewhere. It's not a crisis.*

Commissioner, additional area

We also spoke to HIV services in Scotland and found that a scoping project there had cautioned that a mass population campaign aiming to influence behaviour for HIV prevention could risk causing fear and increasing stigmatising attitudes (Coia et al 2014). Instead, the Scottish government is developing capabilities for assessment and interventions tailored to individuals at high risk of acquiring HIV (Scottish Government 2015).



In all of the areas, people we spoke to had a strong interest in PrEP and its contribution to future HIV prevention. Although each area had different priorities, they all highlighted concerns about levels of public knowledge about HIV, particularly among children and young people, with a consistent view that more sex and relationships education (SRE) in schools was needed. This is in line with the national survey of public knowledge and attitudes towards HIV ([National AIDS Trust 2014](#)), which found significant gaps in knowledge. Some myths, such as a belief that HIV is transmitted by kissing, have increased since previous surveys (16 per cent of the public believe HIV is transmitted by kissing). The government has recently announced that all secondary schools in England will be required to teach relationship and sex education; and personal, social, health and economic education will be mandatory for all schools ([Department for Education 2017](#)).

Detailed information about how a person acquired HIV is collected when clinicians take new patients' histories. There is growing interest in using this information to analyse missed opportunities for prevention – akin to root cause analysis of untoward incidents – and then target prevention activity on those root causes ([Horn et al 2016](#)). We did not find any evidence that this type of information was driving local prevention activity, which was informed only by public health datasets (which, although of high quality, are less detailed and less timely). These disconnected information sets used for different purposes were an indicator of both the difficulty and the potential benefit of aligning efforts across organisations to a common purpose.

### Implications of our findings

Biomedical secondary prevention, such as use of ART and HIV testing, is being prioritised and becoming increasingly widespread, which needs to continue. Primary prevention aimed at influencing behaviour and knowledge is unfocused or lower priority. Primary prevention is clearly difficult; the messages about risk are complex because, for example, a person with HIV and receiving treatment may have less risk of transmitting the virus than someone who tested negative at their last HIV test but has had new sexual partners since. However, primary prevention is also essential, given the trend of increasing incidence of HIV and of other STIs, particularly among gay and bisexual men, and the significant gaps in public knowledge. Although there is a national HIV prevention programme funded by Public Health England, there is a need for further support to local areas from the





national bodies if they are to make progress on this difficult issue. For example, greater clarity about effective interventions, setting expectations, and supportive policies in areas such as SRE could all make a difference.

The Do It London programme for HIV prevention was a notable example of dynamic prevention activity, and was in the process of expanding to address sexual health more widely. It was also the only example we found where all the NHS and local authority interests came together in one place to co-ordinate activity across London as a system. It was likely to offer learning for others on navigating across multiple agendas and on strategies for bringing those agendas together around shared objectives for preventing HIV.

Despite an increased focus since the 2012 reforms on HIV in public health as well as in secondary care, we did not see interventions aimed at broader determinants of vulnerability to HIV.

PrEP has significant potential to prevent HIV, and rapid progress is needed to clarify how this can be achieved and the success factors for using it most effectively. A situation where it is only available to those able to pay for it – despite meeting cost-effectiveness criteria for use in the NHS (McManus and Harrison 2016) – would create a risk of fundamental inequity.

No single method of prevention, on its own, is a ‘silver bullet’ that can prevent the continued spread of HIV; combined approaches are needed. This is made more difficult by the split between responsibilities for HIV prevention (which sit with local authorities) and the expertise about HIV and responsibility for ART (which are located in the NHS). There is a need for leadership that traverses NHS and local authority responsibilities and organisational boundaries to ensure an integrated response to the challenge of preventing HIV. However, that is exactly what the fragmentation of responsibilities brought about by the 2012 reforms has made more difficult.

The judicial review over PrEP also illustrates the risks involved in redesigning structures and the allocation of responsibilities without thinking these through carefully enough, or what the Department of Health’s role was as an arbiter between other system leaders. In the end, it was up to the courts to decide, which not only caused delays in decision-making but damaged trust between organisations that need to work in partnership if HIV prevention efforts are to succeed.





## Testing and entry into care

### What is the context for testing and entry into care?

Tests to assess HIV status have developed over the years and can now be done rapidly, including finger-prick samples with immediate results, confirmed through more detailed laboratory analyses. Increasing rates of testing, and promoting regular testing for key groups, are seen as priorities because early detection and treatment of HIV not only improve individual outcomes but also prevent onward transmission. Many areas of England are introducing home testing and home sampling, enabling people to receive test equipment by post and either test themselves or send a blood sample to a central laboratory and receive results by telephone or text message.

Antenatal screening for all pregnant women across the UK has enabled effective treatment and virtually eliminated vertical (mother-to-baby) transmission of HIV. However, testing programmes alone are insufficient to enable reduction in HIV across the general population; primary prevention is still necessary. For example, it is estimated that in order to reduce the incidence of HIV to less than 1 per 1,000 aged 15–59, at least 90 per cent of gay and bisexual men would need to test annually, and those who tested positive would all need to commence ART immediately (Phillips 2015; Granich *et al* 2009). But there is a long way to go to achieve these sorts of testing rates. The National Survey of Sexual Attitudes and Lifestyles, carried out between 2010 and 2012, found that only 14 per cent of all men in higher-risk groups had had an HIV test in the past year and only 25 per cent had ever tested. In the population as a whole, 3.5 per cent of all men and 5.4 per cent of all women had tested in the past year (Sonnenberg *et al* 2013).

In addition to HIV tests in HIV or sexual health clinics and home testing, HIV tests are also carried out in primary care and as part of investigations for treatment in hospital. In areas of high or extremely high HIV prevalence, they should be routinely carried out for new patients registering with a GP, people attending accident and emergency (A&E) services, and those admitted to hospital (NICE 2016a).

Late diagnosis of HIV is a significant problem, both at the individual and population levels. A diagnosis is defined as late when CD4 cells reduce below 350 per  $\mu$ l of blood. People diagnosed with more advanced infection have poorer clinical outcomes, including higher death rates, than those diagnosed earlier in the course of infection (May *et al* 2011). Those with undiagnosed, and thus untreated, infection remain



infectious to others. There are wide variations in rates of late HIV diagnoses by population group and by region, ranging from 12.5 per cent to 75 per cent in different areas of the country (area sexual and reproductive health profiles are regularly published online at <https://fingertips.phe.org.uk/profile/sexualhealth>).

Following a positive HIV test, patients need significant contact with specialist HIV care teams working together to identify the best personalised package of care, including the initiation and monitoring of appropriate ART. HIV support services are particularly important at this stage, providing information, counselling and other psychological support, peer support and approaches to self-management (NHS England 2013). There is a strong evidence base for a range of benefits from different types of support service (National AIDS Trust 2017a). However, the funding of HIV support services in England has reduced by 28 per cent between 2015/16 and 2016/17 (National AIDS Trust 2017b).

### What did we find in our fieldwork?

All of our case study areas were participating in a national scheme funded by Public Health England to encourage home testing and home sampling, and all were giving high priority to increasing testing rates. We consistently observed momentum and progress being made in increasing HIV testing within sexual health services. HIV specialists were engaging with other clinical services and primary care, but increasing and normalising HIV testing in these environments was seen as a long-term proposition, which did not have the same sense of confidence about making progress.

*And we can see quite clearly, that [home testing and sampling] as an intervention has really positive benefits, in that we can get large numbers of people tested, at low cost, and often, people who wouldn't have tested otherwise. And getting a reasonably good positivity rate, subsequently... This idea that, actually, rather than having to go to a clinic, and waiting, maybe two to three hours, to have your test and a screen done, that actually, it's delivered to your home, and you can do the test, by either taking the samples, or doing the testing yourself at home... That has really positive benefits, because it fits in with the lifestyles of many of the individuals that we want to reach out to...*

National stakeholder



In focus groups, people mostly talked about HIV testing as an exceptional event after a risk exposure rather than a regular, prospective thing (although some people did also talk about it in those terms). Some also described how fear of contracting HIV put them off getting tested, and how they felt there was stigma associated with attending a clinic to test for HIV (and other STIs). Focus group participants and staff both described how negative tests were often seen as meaning ‘no action needed’, whereas best practice is for it to lead to assessment of how to stay negative and when to re-test (Horn *et al* 2016).

*I was diagnosed [with HIV] in about mid-March this year. [I] acquired it [on] new year’s day. I started having symptoms about three or four weeks in, which brought some concern, but I didn’t know how to bring myself round to testing until the start of March.*

Person living with HIV, case study area C

In London, plans were being developed to reduce testing activity in sexual health clinics, instead making home testing and sampling the main approach. This was informed by market research, which indicated the general acceptability of that approach and, in many cases, preference for it rather than attending an outpatient clinic. It was presented to us as innovative but with a continuing need to manage the risk being taken in introducing change at this scale, given that its impact in practice is unknown.

Focus group participants attached very strong importance to HIV support services, particularly around the time of receiving a diagnosis but later on too. This is partly to be expected, as some focus group members were recruited through support organisations, but their descriptions of the importance of these services were vivid; they were also reflected in what staff and stakeholders told us, and are in line with other study findings (Ejbye and Homan 2016; British HIV Association 2011; Advocates for Youth undated).

*Now I feel I could talk to any of my friends about what happened and be quite comfortable with them knowing and all the rest of it. But for a certain period of time it was ‘that’s a rock that you just don’t let anyone look under’ and that’s quite... I think it can be dangerous if there isn’t that place to go to [ie, the support service] because you just... Yeah, you get in a very dark place with no one really understanding why you’ve gone there. It’s vital.*

Person living with HIV, case study area B



There was also deep concern about the future of HIV support services. In one case study area, local authority funding had been under threat but, in response to lobbying, was being retained for 12 months pending a further review. In another case study area, a consultation was in progress on the possibility of commissioning generic rather than HIV-specific support services, with financial pressures a key factor.

In the rural case study area, there were no HIV-specific support services despite attempts in the past to establish them. In focus groups, people who had moved to or from rural areas without support services described this as a significant gap in meeting their needs compared with their experience in towns.

*Because I'm in [rural case study site] other services seem to be [nearest major city]-based. [Clinical nurse specialist] had mentioned that there was a group that meets at [name] cinema in [nearest city], but it's an evening thing and the transport side for me would be difficult because it would be an hour and a half [there] on the bus and then the buses stop earlier. And getting home, I would potentially not be home until after midnight depending on what the event was. I did search on Google for groups in [region] and I couldn't find any, apart from [nearest major city].*

Person living with HIV, case study area A

## Implications of our findings

The progress being made in increasing HIV testing is encouraging and needs to continue and go even further. It needs to focus on helping people stay HIV negative, as well as the current emphasis on detecting people who are HIV positive in order to get them on treatment and thereby prevent onward transmission. Testing is a crucial part of a multi-faceted, strategic approach to HIV prevention.

Without downplaying the good progress so far, there is some way to go before HIV testing could be considered routine even in at-risk population groups, and especially so in non-HIV specialist services. Home testing and home sampling are positive developments, but the lack of human interaction could limit opportunities to influence attitudes to routine testing and to develop strategies to prevent people acquiring HIV after receiving a negative test result.



There is a debate to be had about whether specialist HIV support services are needed (rather than more generalist services), and how to assess their roles and effectiveness as treatments and models of care evolve. These issues should be decided by listening to people with and at risk of HIV, as well as taking into account the contribution these services make to the overall effectiveness of care and prevention. But what we heard suggests that, in some cases, financial pressures may result in commissioners taking a unilateral approach on the basis of their fiscal circumstances alone. The significant reduction in funding for these services nationally is worrying ([National AIDS Trust 2017b](#)).

## Ongoing treatment and care

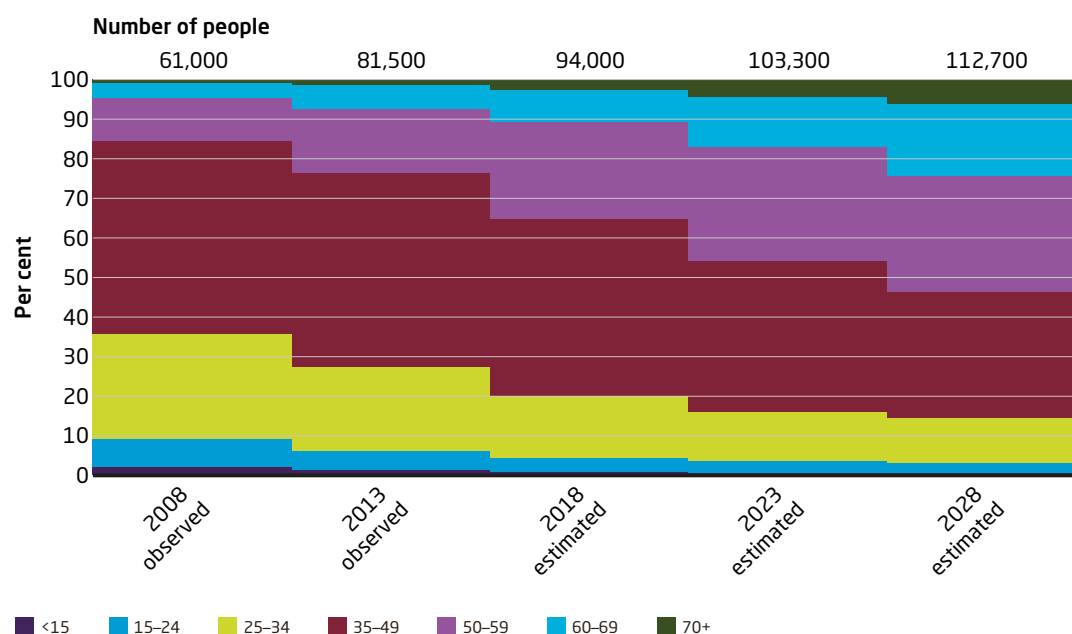
### What is the context for ongoing treatment and care services?

Nowadays, for the overwhelming majority of people living with HIV – estimated as around 85 per cent to 90 per cent of the total (ie, those who are not newly diagnosed and do not have complex needs) – specialist care episodes are becoming less frequent. For virologically stable patients, monitoring may only be needed every six months, and this group of patients is potentially able to self-manage. This group is growing in number and, within it, the proportion of those aged over 50 is increasing rapidly ([Yin \*et al\* 2015](#), see Figure 6 below).

The likelihood of other long-term co-morbidities alongside HIV (such as cardiovascular disease, liver disease, neuropathy and osteoporosis) increases as people grow older (Deeks *et al* 2013). Some of these co-morbidities are common to all people growing older; others may be caused or exacerbated by HIV or ART. However, long-term care for people with HIV is still a new phenomenon and knowledge is still developing on how best to manage the complexity of caring for people with HIV for much of their lives.

In the 1980s and 1990s, specialists provided all aspects of treatment and care for people with HIV. Since that time, as people live longer and have other health needs alongside HIV, other services have become more involved. Primary care teams, which often have a key role in co-ordinating treatment and care across different conditions, have developed some notable examples of shared care between specialists and GPs for people living with HIV and other conditions (for example,

**Figure 6 Actual and projected age distribution of people receiving HIV specialist care, United Kingdom, shown as numbers and percentages**



Source: Yin *et al* 2015

**Royal College of General Practitioners (RCGP) 2016** or papers for the 2016 British HIV Association (BHIVA)/RCGP conference available at [www.bhiva.org](http://www.bhiva.org)). But the role of GPs in relation to HIV is mostly poorly developed, due to a number of barriers to effective shared care. MacLellan and colleagues (2017) identified these as lack of well-established relationships between HIV specialists and GPs, complex commissioning arrangements, patients' lack of trust in primary care and concern about stigma, incompatible IT systems, and lack of time, training and resources. We would add to that list a lack of clear local and national system leadership to drive progress forward.

For some patients, complex clinical, psychological or social needs mean that there is a much greater need for specialist multidisciplinary care. Wellbeing as well as adherence to treatment among these patients requires significantly greater input from the HIV consultant, clinical nurse specialist and HIV support organisations, with a consequentially narrower role for GP input.



Clinician interviewees told us that probably fewer than 100 people at any one time require highly specialised inpatient care for HIV-related illness in England. However, precise figures are not available because the reason for admission to hospital is sometimes recorded as the HIV-related illness requiring immediate treatment, rather than the person's underlying HIV-positive status. There have been repeated reviews in London attempting in particular to establish the number of inpatient places needed and the best way to organise such small and very highly specialised inpatient services. However, none of their recommendations have been fully implemented.

### What did we find in our fieldwork?

People in our focus groups gave consistent and strong appreciation of the quality of care received from specialist HIV services. This is in line with national patient survey findings, which report 96 per cent satisfaction (Kall *et al* 2015). The importance of HIV support services, and the importance of ongoing access to social and psychological support, were also consistently emphasised.

*... when you go through [those] first... two years of adjusting [to HIV diagnosis], you build that strong relationship. You trust what [the consultant] is telling you and the things he's saying. And he basically has to guide you from whatever the feeling is you could be experiencing at the very beginning when you're told, to you are now comfortable living with it... And just knowing that you are going to meet somebody who knew your case, knew who you were, made the effort to ask you, 'How's uni going? How's your parents? How's your brother? How's that job? Did you get it?'... He knows all of that and that side of the HIV [care] is actually quite important.*

Person living with HIV, case study area B

Although there were notable exceptions, only a few of those we spoke to had positive experiences of primary care and many did not have confidence in their GP. This contrasted sharply with the praise given to specialists. Other studies have similarly found a mixed or mostly negative picture of satisfaction with primary care from people living with HIV (MacLellan *et al* 2017; Miners *et al* 2016). Some of the concerns expressed to us related to broader pressures on primary care (difficulty in getting appointments, rushed consultations, lack of continuity). Others related to knowledge about HIV and ART, insensitivity to the psychological impact of HIV





and the stigma associated with it, or a feeling of being treated differently because of having HIV.

*The GPs here, they don't ask you nothing, they're not interested. All they're doing is waiting for the next person to come in. My doctor here has never ever once asked, 'How are you doing?' All they do is give out the script, because they haven't got time. They've got five minutes basically and you can see them looking at their clock and they've got to see somebody else in a few more minutes.*

Person living with HIV, case study area D

When we spoke to staff in our case study areas and to stakeholders, there was no clear sense of what the model of long-term care for people with HIV should look like or how to achieve it. Specialists were concerned about the risk of diluting the quality of the current service if it became more integrated with primary care. Specialists and GPs alike drew attention to the pressures that primary care is already under (Baird *et al* 2016), raising questions about how GPs could take on additional roles in that situation.

*The shift has been for people to be encouraged to share their [HIV] positive [status] with their GP, which I think is a really positive thing, but they're still not really engaged in their care in the way that they maybe [are] for other conditions. Again I think you're going to have to get some brave people to take it on and show it can work and that the shared care model could possibly work. I haven't got any answers; I just know that, as I say, it's an aspiration.*

National stakeholder

The most frequently expressed view was that while progress had been made in recent years and some GPs were fully engaged and working closely with specialists in caring for people with HIV, most were not; but the pioneer GPs might, over time, engage their peers and be role models for future changes in practice across primary care. There is evidence that change encouraged in primary care by pioneers within the sector can be more effective than exhortation from outside it (Smith *et al* 2013; Goodwin *et al* 2011), but we did not hear of specific plans to support or facilitate a process of that kind or of defined objectives. The main reason for the views that we heard was that most GP practices (even in cities) have small numbers of patients with HIV, and HIV is likely to remain a minor part of most GPs' work for the foreseeable future.





*I think it's difficult to understand what it might actually be like to be a GP in an area of low HIV prevalence. You're not going to necessarily know you've got anybody in your practice population with HIV, or if you do, then you know about one or two. If you're presented with the opportunity to do training on something, why would you choose HIV when it's such a small-scale issue compared to all the rest?*

National stakeholder

Another reason for low levels of engagement with GPs is that HIV services have historically been self-contained, providing all aspects of care themselves. Run largely from within sexual health services, they have processes, information systems and ways of working that are different from other hospital departments and have only fairly recently started to join these up with other services. Being commissioned nationally, HIV services are poorly engaged with CCGs, who were only involved in HIV services at all in one of our four case study areas. HIV clearly meets the definition of a long-term condition ([National AIDS Trust 2016a](#); [Department of Health 2015a](#)). Many of the issues that we observed (such as concern about co-ordinating care over multiple co-morbidities) are exactly mirrored in policy and the 'house of care' framework for long-term conditions. However, HIV is not included in national policy ([Department of Health 2015a](#); [Health Committee 2014](#)) or guidance on long-term conditions ([NICE 2016b](#)).

### Implications of our findings

There is potential for HIV services to benefit from the policy, guidance and practice that have already been developed for long-term conditions – and a risk of duplicated effort and difficulty in joining up with the management of other co-morbidities if this does not happen. Other long-term conditions services could equally learn from the HIV sector – for example, from its experience of involving and empowering patients and communities and its perspective on how specialist and GP roles are interrelated. However, this issue needs careful consideration and communication. We heard that there is a perception in some areas that moving towards a long-term conditions approach would serve to 'downgrade' HIV services to make them more generic and less specialised. All of the specialists that we spoke to were clear that with long-term care of people with HIV being such a new phenomenon, and the newness and complexity of ART medicines, HIV will continue to require specialist oversight for the foreseeable future.



These views – alongside the history of HIV services being self-contained and the pattern of repeated reviews in London that have failed to be fully acted upon – suggest that there is likely to be resistance to change in how HIV services are organised among some professionals and patients.

We found examples in case study areas and in interviews with stakeholders where both the local and national approaches lacked focus and purpose when they tried to go beyond recognising the need to develop new models of shared care and workforce roles to actually defining and implementing them. In these cases, the discussion had potential to drift rather than enabling services to keep pace with the changing needs of people living with HIV (which is the key reason for services needing to change in the future). There is an important leadership role here, at local and national levels, to articulate future models for HIV treatment and care and to lead the process of change towards them, ensuring that service providers and service users are on board.

The approach to developing future models of care will need to start small and avoid grandiose or over-ambitious scales. Engagement and relationships with primary care and other clinical teams will need to be built up over time. The basic processes for sharing information and ensuring good quality of communication would be a good place to start, given their current unreliability and diversity.

The small numbers of patients with HIV at GP practice level represent an opportunity as well as a challenge, in that there is time to develop, test and evaluate different models for shared care before numbers become larger. There are already pioneering HIV and GP services working together, which are well placed to lead on this. However, national leadership will be needed to co-ordinate these efforts, to evaluate and disseminate the learning from them, and to scale up successful approaches.

## Interfaces with other services

### What is the context for developing interfaces with other services?

In addition to primary care, discussed in the previous section, HIV services have significant interfaces with sexual health, mental health, and drug and alcohol services. As people live into older age with HIV, services also increasingly interface with other hospital services that treat co-morbidities, and with social care services.



The interface with sexual health directly affects patients (eg, greater convenience if information about risks can be given in one place). It also impacts on prevention activity (eg, separation of HIV and sexual health services may reduce the ability to gain a full view of risk behaviours that are common to HIV and other STIs). Interfaces have differing levels of importance for different population groups and will need to be managed differently in different areas (eg, the interface with sexual health is particularly important for HIV services where gay and bisexual men are a key group). In integrated HIV and sexual health services, the same staff work across both specialties, although they are commissioned separately. Following the 2012 reforms, a number of HIV services in England became too small to be viable and had to be taken over by larger providers at short notice, usually after the previously integrated sexual health service was awarded to a different provider following competitive re-tendering ([APPG on Sexual and Reproductive Health in the UK 2015](#)).

Co-ordination with mental health and drug and alcohol services is particularly important because people living with HIV have higher rates of psychological difficulties and mental health-related co-morbidities than the general population ([BHIVA 2011](#)), and because these services can have a role in identifying people who are vulnerable or at high risk of acquiring HIV ([Coia et al 2014](#); [Public Health England 2014b](#)). Given the high levels of unmet social need among people with (or at risk of) HIV, effective links with social care are fundamental to good care.

These non-HIV-specific health services are generally commissioned by CCGs. Sexual health and drug and alcohol services, however, are commissioned by local authorities, as are social care services. A number of policy documents have recommended giving consideration to integrated commissioning and pooling of budgets across health services and across NHS and local authority responsibilities in order to help join up care for HIV and more generally ([Humphries and Wenzel 2015](#); [Addicott 2014](#); [Public Health England 2014a](#); [Commission on the Future of Health and Social Care in England 2014](#)).

### What did we find in our fieldwork?

We found that, in practice, there was variability in how closely services worked together, although the need to do so was well recognised in principle. The issues were very similar to those that occur in other long-term conditions – for example, co-ordinating treatment or sharing information. As such, they also correspond to



the ‘house of care’ framework, which NHS England has adopted and is designed to help manage care across long-term conditions (Coulter *et al* 2013; NHS England 2016e). We did not see that this was a new issue, but it is certainly becoming more visible as the numbers of people with multiple co-morbidities increase.

A recurrent theme in focus groups was people describing how they could be ‘passed from pillar to post’ and end up themselves having to ensure that information was shared because it did not happen systematically. In one area, a system was in use (designed for long-term conditions management) that enabled different providers to share electronic patient records and for the patient to see all the different records.

*So I’m treated at [hospital 1]. I live in [London borough] so [hospital 2] is my local hospital... In terms of my GP, they’re very happy with me being treated at [hospital 1] and as far as they can they’ll facilitate all my treatment at [hospital 1], but the two systems don’t talk to each other. So I also have my endocrinology, which was being done at [hospital 3] and I have some oral issues that were being treated at [hospital 4]. I have literally been seen twice in the same week for exactly the same blood test.*

Person living with HIV, case study area D

We found that although there have been rapid increases in the numbers of older people with HIV, social care providers and social care commissioners were not engaged with HIV services systematically in any of the areas we visited.

In one of our case study areas, the sexual health service and HIV service had been awarded to two different providers. The two services were located nearby, and this was felt to reduce the inconvenience to patients who needed to use both of them. However, it led to staff in both services putting in significant extra effort to encourage patients to attend the other clinic as well; to negotiate direct referral arrangements; to co-ordinate treatment interventions; to share information; and to manage workarounds and create flexibility in working together rather than being too rigid about contractual requirements. More generally, we heard repeated concerns about the potential knock-on effects for HIV services if integrated sexual health services were contracted to a different provider, including financial sustainability and the longer-term implications for the workforce (such as attractiveness of posts for recruitment and training).



We were told that the approach to tendering in sexual health services – which usually treated providers as competitors and information as commercially sensitive – drove a set of behaviours that could reduce sharing of strategically useful managerial information. For example, understanding the variation in roles undertaken by consultants and clinical nurse specialists – which is also occurring in some other specialties as follow-up to Lord Carter’s review of operational productivity ([Department of Health 2015b](#)) – could not only help manage variations in costs but also inform strategic workforce planning. But this would require data to be complete across integrated HIV and sexual health services, and that data to be accessible.

In the areas that we visited, we did not find that integrated commissioning had developed across NHS and local authority sexual health and HIV services. We were also told that arrangements to co-ordinate the commissioning of sexual health, HIV, mental health, and drug and alcohol services had reduced since the 2012 reforms. Nearly four years after those reforms started to be implemented in 2013, this lack of progress was in contrast to developments in other parts of the NHS where there were signs that pooled budgets, risk-sharing agreements and capitated budgets were starting to be explored in several areas since the *NHS five year forward view* (Forward View) was published ([NHS England et al 2014](#)). Ministers have recently announced additional support for integrated commissioning ([Hansard 2017](#)).

We found that interfaces with neighbouring areas (as well as with other services) had become increasingly important. In one area we visited, a single provider that covered two local authorities had different service specifications for each, which was causing staff in the integrated HIV/sexual health service to divert efforts into managing this. Some staff perceived it as a postcode lottery of access to services.

*We’ve got slightly different commissioning, we’ve also got slightly different things that have been commissioned, so it gets very bizarre. So, for example, their local authority has said we want this, and our local authority has said slightly different things. So what we’re funded to provide to a patient [here] may be different from down the road, yes, or depending on which clinic they go to. That’s where it gets really, really bizarre. Patients don’t know [about] it. We’re all reeling, really, because we felt that we had a good service and now bits are being chopped off.*

Provider, case study area A



Staff in London made similar observations about the variability of access to HIV support services from one borough to the next. In London, service evaluation had shown benefits in effectiveness from a single, consistent approach to prevention. By the same token, this highlighted that there could be a risk of fragmented, confusing messages if local areas did not co-ordinate their approach with neighbouring ones.

### Implications of our findings

The difficulty of co-ordinating care across multiple co-morbidities is well known and leads to poor experiences for patients if not managed well. But frameworks and processes have already been developed for managing it in other long-term conditions services ([Coulter et al 2013](#); [NHS England 2016e](#)). HIV services could make use of these existing frameworks and adapt them as needed, taking account of the unique features of HIV and the diverse needs of different key populations in each area.

HIV services are becoming less self-contained. Continuing to develop partnerships with other service providers and commissioners will be essential if care is to be integrated around patients' differing combinations of needs in the future. Supporting this change in ways of working for HIV specialists and others will be a key task for system leaders. It may need to include new partners – notably social care services and, possibly in the future, older age physicians – as well as ones that have already been identified.

Although HIV treatment services are all commissioned to a national specification, most of the services that they join up with are commissioned locally. There is currently limited engagement with CCGs and local authority commissioning teams for social care, which is hindering co-ordinated planning.

Care needs to be taken to avoid the risk of postcode lotteries (where neighbouring areas have commissioned different services), and to explain the reasons for differences.



## System management and leadership

### What is the context for developing system management and leadership?

By system management and leadership, we mean the arrangements to ensure delivery of HIV services and the roles that leaders take, across a local area or at national level. It includes overseeing and guiding the ways in which treatment and care services, public health and commissioning all work together and involve people and communities.

At national level, the system leaders are the Department of Health (responsibility includes overall policy), NHS England (responsibility includes commissioning treatment services, service strategy and performance information) and Public Health England (responsibility includes public health data and guidance). The Local Government Association (LGA) shares learning, provides guidance and facilitates peer improvement for local authorities. At local level, areas decide on leadership roles across organisations and system management arrangements depending on their circumstances. Guidance has been issued to support this ([Public Health England 2014a](#)), and case studies of notable practice have recently been published ([Local Government Association and Medical Foundation for HIV and Sexual Health 2015](#)). Health and wellbeing boards decide local strategies for health and wellbeing and, more recently, 44 regions have developed STPs, which provide an overarching, cross-system framework for NHS services to develop and work with other partners ([Alderwick et al 2016](#); [NHS England et al 2015](#)).

Currently there is no national HIV strategy, but there is a framework for sexual health improvement ([Department of Health 2013](#)). It sets out limited ‘ambitions’ relevant to HIV such as increasing knowledge about sexual health, reducing STIs, remaining healthy, priority for prevention, and reducing onward transmission of HIV (the latter is the only HIV-specific ambition). These ambitions are unquantified and have no timetable or indicators of progress.

Arrangements at national level for system management of public health generally, and in particular accountability, have been criticised by the Health Committee ([Health Committee 2016](#), p 30):

*... there appears to be a disconnect between the official ambition to deliver significant savings through a radical upgrade of public health and prevention*





*and the lack of rigour in implementing this ambition, with little systematic monitoring of local authorities' progress towards specific public health goals at a national level.*

APPGs have similarly criticised the complexity and fragmentation of commissioning arrangements for sexual health and HIV (APPG on HIV and AIDS 2016; APPG on Sexual and Reproductive Health in the UK 2015). However, the temptation to presume that all was working perfectly before the 2012 reforms should be avoided. The Health Committee inquiry into commissioning in 2011 – before the reforms took place – heard very similar concerns about fragmentation and poor co-ordination of the commissioning of HIV services with other health care services. Numerous vested interests were described, which held back the development of service models for HIV, with insufficient system leadership and governance to overcome them, resulting in variability in how well specialist HIV services co-ordinated with others (Health Committee 2011). Far from the period prior to the 2012 reforms being a golden age, many of the recent concerns about commissioning and system leadership were present then too. The greater clarity that we now have about the need for HIV services to change and adapt to the increasingly long-term nature of HIV care has further highlighted their importance.

### What did we find in our fieldwork?

In all the areas we visited, we saw examples of effective leadership within services – for example, leading to developments such as telemedicine consultations, radical improvements in the accessibility of HIV testing, and outreach to key population groups. But we only saw notable leadership arrangements *across* services and *along* the HIV pathway in one area. In that area, a programme board brought together all the providers and commissioners and patient representatives and co-ordinated work on a single, shared plan for HIV and sexual health. With third sector partners, they were consulting on a strategy with targets for reducing HIV-related deaths, new cases of HIV and stigma.

It was noticeable that in this area, relationships were close and morale was good. Providers and commissioners had, for example, made a determined effort to use re-tendering of sexual health services as an opportunity to review services to ensure that they were as good as possible. We heard that overall it had been a positive





experience. In the other areas that we visited, re-tendering was probably the single biggest challenge and its competitive nature had damaged some relationships and morale.

In some cases, the lead individuals in different organisations had not all met one another, or some had only met once or twice since the new arrangements started (nearly four years ago).

*It feels like we're in a silo and we're not really talking to each other about what the expectations are, and it's only when something comes up that it's actually, 'Who pays for this?' 'Do we pay for it or do they pay for it?'... where there's actually communication takes place. I think that's a big problem in that we don't really have joint meetings or... we probably all hold our own performance indicator meetings separately.*

Commissioner, case study area A

In these areas, the lack of joint working was readily identified as a problem, but there was no clarity about who had authority to address it. We asked in all areas whether health and wellbeing boards could take on this role, but we heard consistently that they attempted to address too many topics, each only at a high level, and are therefore lacking in impact.

We heard repeatedly, at both local and national levels, the view that national bodies should 'do more', but there was no clarity about what that should actually look like. There was, however, consensus that it should not be top-down management or another restructuring.

NHS England's role in system leadership for clinical services was praised and there was optimism for its new HIV clinical reference group, which had recently been expanded. However, commissioners in general and NHS England's area teams in particular were felt to have become too thinly spread across very wide portfolios to be able to provide effective leadership. NHS England did not always have capacity locally to attend meetings and contribute to discussions. CCGs were only engaged at all in one area.

Public Health England's role in surveillance and data provision was welcomed, but there were different views on its role in guidance and funding activities (for



example, through the National HIV Prevention Innovation Fund). Some felt that it was insufficiently assertive in its advice, and wanted it to do more. Others told us that it should either stick to just advising, or should improve co-ordination of the services it funds. Public Health England regional centres could have valuable roles in bringing different parties together and influencing local priorities, but we heard that this depended on the interest and engagement of particular individuals and was variable.

We asked in all areas about the process of developing STPs, but none of the HIV services were engaged in it. This partly reflects the early stage of the development of STPs and a broader pattern of low engagement of frontline staff in STPs at that time (Ham *et al* 2017). We have been told that engagement has since increased.

### Implications of our findings

The challenges we found – including defining the model for long-term HIV treatment and care, planning for greater numbers of older people living with HIV, and focusing primary prevention efforts – will be difficult to progress without local co-ordination and plans, and national dissemination of learning. The continued lack of these basic foundations in some areas, and the right quality of relationships to enable them, are worrying.

Severe financial pressures, for local authorities in particular, clearly have a bearing. Not only is capacity under pressure – seen, above all, in the breadth of individual commissioners' responsibilities – but local authorities' re-tendering of sexual health services is also having to require significant cost savings. While we heard this has led to some welcome scrutiny and innovation in services that have not been assessed for years, it is also causing 'fortress mentalities' in some sexual health and HIV providers, leaving insufficient space and time to invest in the leadership, relationships and new ways of working that are needed to develop future models of HIV services.

There are significant risks if commissioning decisions are made without consideration of how the knock-on implications for other services will be managed (for example, if staff such as health advisers are separated off into a different sexual health provider from the HIV services). These risks are already occurring, and their consequences could become more severe when the current ring-fence for local authorities' public health funding (which includes sexual health funding) is



removed. The recent announcement of an extra ring-fence year (2018/19) provides the opportunity for the Department of Health to spend more time thinking this through.

While one of our case study areas shows that system leadership and governance arrangements can be put in place successfully at local level, the others show that greater clarity about expectations and accountability are needed. This suggests that rather than relying on localism, as was largely envisaged in the reorganisation of responsibilities in the 2012 reforms, there is an important role for national oversight bodies in HIV services. Alternatively, that role may be taken up by STPs at a regional level, depending on how much their role evolves in the future to provide strategic direction and accountability, and how they relate to non-NHS commissioners and services.



## 4 Wider reflections on our findings

Before considering what our findings mean for the development of HIV services in the future, in this section we pause to reflect on the findings from two perspectives.

- First, we review the unique situation of London, where, although some of the key challenges to HIV services may be similar to those in other areas, they are considerably magnified. (London is considered in more detail in Appendix B.)
- Second, we reflect on those areas where the development of future HIV services may benefit from working in closer partnerships and sharing learning with other services, as well as contributing their own learning to the benefit of those other services.

### Reflections on the challenges facing HIV services in London

Almost half of all people who receive treatment for HIV in the UK do so in London. The rate for new HIV diagnosis in the capital is more than three times higher than any other area; the population with HIV is more diverse than anywhere else in the country; and there are more people living into older age with HIV in London than anywhere else in England.

This unique combination of scale, complexity and diversity magnifies and makes more explicit the challenges facing HIV services. Trends in epidemiology and behaviour are often seen first in London (at least at scale), as are the clinical and wider responses to those trends.

London provides some of the world's best clinical care and outcomes for patients, and excellent surveillance on HIV, but the systems underpinning this have some exceptional challenges. To what extent do these challenges apply, perhaps at a less extreme scale, in other areas of the country, and how prepared are those areas to manage them?



### **Good public health surveillance alone is not enough**

London's HIV and sexual health services are undergoing a form of stress testing: extremely high incidence of HIV and STIs, at the same time as financial pressures on local authorities and the NHS, and uncertainty caused by re-tendering of sexual health services and reviews of HIV service configurations.

There is a continuing 'slow-burn epidemic' of STIs, and continued high incidence of HIV and of late diagnoses. These are also issues of equity as they affect some population groups disproportionately, such as the striking increases in gonorrhoea among gay and bisexual men.

The scale of the problem has been well documented, by Public Health England in particular, for some time. But it is not clear who has authority to change the situation and ensure that trends are reduced or reversed across the city.

#### **Reflections**

- How can public health information join up robustly with capability and authority to act on that information across the area?
- How can responses to major public health challenges be effective when responsibility is fragmented rather than co-ordinated or integrated, especially when they are in competition with other major pressures for resources, and when they involve a communicable disease that will not stop at administrative boundaries?

### **A fragmented system will not come together unless system leaders actively make this happen**

There were two pan-London reviews in process at the time of our fieldwork. Both are significant in terms of their scale and complexity: NHS England's HIV specialised commissioning review covers 18 providers, and the London Councils' Sexual Health Transformation Project covers 29 of the 33 boroughs.

Each may be internally logical and coherent but there is no overarching strategic relationship between these reviews, no joint agreement on the overall goal, and no



co-ordinated process to ensure that the individual outcomes result in a better, more efficient overall pathway of care for people with HIV and STIs in London.

There is a history of reviews of HIV services in London whose recommendations have not been fully implemented, and a large cohort of professionals and patients who have established ways of working together over many years. There is likely to be some resistance to change within this dynamic.

#### Reflection

- What are the best ways to get the full range of interests on board and ensure that strategic plans and activities are co-ordinated?

### **Fragmented responsibilities make it harder to plan strategically**

There was a fourfold increase in the number of people in London over the age of 50 living with HIV in just 10 years from 2004–14, and the trend of rapid increase is continuing. Despite the demographic shift that has already started to happen, there is little evidence that services in London are engaging with patients about what this means and planning ahead across health and social care services for older people. This may not be a result of the 2012 reforms, but the reforms have not helped, as there is nowhere in the new structure that is a natural home to strategic, cross-sector planning.

#### Reflection

- With clear projections of the future numbers of older people living with HIV, who will be users of services across health and social care, and how will local HIV systems ensure that they have plans in good time?

### **Structural changes alone will not make the system simpler**

In addition to 33 boroughs, 32 CCGs and 18 NHS and other specialist health care providers, there are now also five STPs in London as a potential extra layer, plus a role for the mayor in developing a strategy to address health inequalities. Nationally, there is a trend of some CCGs merging, and some NHS trusts working in chains and other new organisational forms. Structures are likely to continue to change and to become even more complex.



## Reflections

- The health and care system is characterised by complex structures, and reorganising them is unlikely to provide solutions on its own: relationships are key to bringing clarity and shared purpose across the system. How can system leaders promote effective relationships across the different elements?
- The Do It London HIV prevention programme has successfully brought a wide range of organisations together in ways that other initiatives have not achieved. What can be learnt from it? Does it create any opportunities as a platform to build on, for developing partnerships further?

## Reflections on learning from experience between HIV services and other sectors

### HIV services have similarities to other services as well as unique features

In the discussions for our research, the unique features of HIV and HIV services, such as the experience of stigma and the fact that they are both communicable and life-limiting, were described more frequently than their similarities with other conditions and services. Yet there are other services, such as cancer services, which similarly range from primary prevention to highly specialised treatment, and include long-term care alongside co-morbidities. Cancer services were also affected by the redistribution of responsibilities along that pathway after 2012 and have a history of developing multidisciplinary team (MDT) processes specifically to co-ordinate care, as well as of involving survivors extensively in their care. Integrated care pioneer projects ([NHS England, undated](#)), such as that in Greenwich, have developed alternative approaches to making care better co-ordinated and person-centred.

HIV services were historically self-invented, to respond to HIV as a new phenomenon. But for long-term HIV care, more partnerships will be needed, and there are already frameworks in place to support these in other service areas. We did not hear anybody arguing that current models of HIV care should be discarded in favour of other models for managing long-term conditions, but there was widespread interest in learning from and adapting, as appropriate, the approaches that other services have developed, rather than re-inventing the wheel.



#### Reflection

- Which services can HIV services learn most from, and how can HIV services engage with those other services locally?

### **HIV services are bringing a new perspective on the balance of roles between specialists, other health services and patients**

Compared to most health care services, HIV services have evolved rapidly when compared to most in response to changes, particularly changes in demography and in treatment opportunities. Specialist HIV care has extremely high rates of patient satisfaction, with successful retention in care and adherence to treatment.

HIV care should be able to learn from and adapt approaches developed for other long-term conditions, and vice versa.

#### Reflection

- How could HIV services share their learning about long-term care with other services for people with long-term conditions, locally and nationally?

### **Fragmentation creates risks when services are undergoing change**

Many commentators have been critical of the fragmentation caused by the 2012 reforms, and it has certainly created complexity and extra work for staff. But the clinical quality of HIV care has held up despite this. The two major changes facing HIV services – changing needs of people living with HIV, and the need to reduce costs where public health budgets are under pressure – highlight the risks of introducing change across services and of unilateral, unco-ordinated commissioning decisions.

#### Reflection

- Fragmented services may be able to maintain quality, at least in the short term, by relying on staff commitment to hold them together. But where services also need to change, is that the key risk that could make negative impacts on patient care inevitable?





## National commissioning in an era of localism

HIV services are among those that need to develop ways of joining up regional planning and commissioning through STPs, along with the national systems that are in place for commissioning specialised services. There is no clarity yet on how this will work, but HIV services and others (especially in London) should be able to contribute their learning. In some STPs, formal reviews and working groups have been established to consider this (Alderwick *et al* 2017). HIV services should ensure that their interests and objectives are considered alongside other specialised services when decisions are made.

### Reflection

- How should national and local roles join up for commissioning specialised services, to meet the HIV sector's strategic objectives?

## The relationship between national bodies and local services is going through a transition

The Health and Social Care Act 2012 attempted to put into practice the vision of an NHS elegantly designed, competitive, and then set free; once designed, it would need no guiding hand on the tiller, only minimal national policy-making – holding the system to account but not running or steering it (Timmins 2012).

But it has not worked out like that, partly because the need to manage austerity arose unexpectedly in the meantime and – specifically for HIV services – because people's needs are changing and the structures for HIV care established by the 2012 Act are not designed to meet those needs. This has made clear that there are still essential roles for national bodies in setting direction and managing broad issues such as workforce development or reducing stigma – issues that are too big to be taken forward only at local level.

### Reflection

- In this report, we present an analysis of the roles that national bodies should play in HIV care and make recommendations to that effect. Our perspective is specifically on future HIV services, but to what extent is our analysis HIV-specific, or does it resonate more generally?



## 5 The way forward for HIV services

In this section we discuss what our findings mean for the future of HIV services in England. We identify the fundamental drivers of change that HIV services will need to respond to. We then make a number of recommendations for local services and national bodies.

- For local services including prevention, we focus on collective system leadership, the development of models of HIV care, and three broad themes: integration of care; alignment with wider place-based policies; and greater connection with existing approaches to managing long-term conditions.
- For national bodies, we focus on the key roles that each body can play in HIV care and actions they should take to take those roles forward.

### Drivers of the shape of future HIV services

A key problem we observed was that the 2012 reforms have led to a distribution of roles and responsibilities that is neither well suited to the specific challenges that HIV services need to address in the future, nor to managing the process of change that will be required. In particular, the system is not geared to helping HIV services evolve to meet the changing patterns of people's needs; in fact, they sometimes make that harder.

The boxes below set out the drivers for change that future HIV services need to address.



### Changes that future HIV services need to adapt to

- **Gains in survival** mean the age profile of people living with HIV is increasing and HIV care is increasingly long term. This adds a focus on quality of life and co-ordinated treatment.
- HIV services will need to join up with the broader move that has recently started towards **integrated, place-based systems of care**.
- There is a need to respond rapidly to the implications of **changes in technologies** (such as PrEP, online testing and telecare), including as patents expire for the current crop of ARVs.
- The **challenges of HIV as a population health problem change quickly over time** as communities at risk change – for example, vertical transmission (from mother to baby) has been almost eliminated, yet chemsex and changing attitudes to risk are growing problems – and patterns of HIV can change rapidly in line with changing population dynamics. The response of HIV services and the bodies commissioning those services need to be nimble.

### Continuing needs, where future HIV services need to do more or do things differently

- There is an ongoing need to focus on the **diversity** of people affected by HIV – including how incidence and prevalence vary in different population groups now and the differing risk that diverse groups face of acquiring it in the future, and people's differing psychological and social as well as clinical needs.
- **Stigma** and poor basic knowledge about HIV remain very significant challenges that help perpetuate HIV and undermine effective responses to it.
- Services must **maximise what is possible from already established good practice**. We have previously referenced the potential reductions in HIV incidence if all prevention strategies with an evidence base were implemented consistently (Punyacharoensin *et al* 2015). National audits conducted by the BHIVA indicate that there is variation in how good practice standards are implemented. There is also too much variation in late diagnosis and too much reliance on the activity of HIV specialist clinics to provide HIV care alone rather than making full use of all available resources.
- **Services are not listening or working closely enough to people living with HIV** about what they value now from current services and what they need in the future. When services are under financial pressure, it is even more important that people living with HIV are partners in deciding how to manage that situation fairly and reasonably.



## Strategic themes and recommendations for HIV services

Future HIV services will need to address all of the fundamental drivers above. In this section, we make recommendations as to how they can do this, by making progress in three strategic themes.

### Theme 1: Reintegrating fragmented services

There is already a wealth of practical guidance on the integration of HIV and sexual health services ([Public Health England 2014a](#); [Department of Health 2013](#)). However, integration will not be achieved by issuing more guidance, but rather by collective system leadership to agree local strategies, and by building and renewing relationships across local places and system boundaries ([Fillingham and Weir 2014](#); [West et al 2014](#)). One of our case study sites was making more progress than the others towards an integrated approach, suggesting that closer integration does not require further structural reorganisation.

There is a need for much stronger system leadership than at present to make integration happen. This cannot be achieved by clinicians, commissioners (whether they be from the NHS or local authorities) or directors of public health alone. It needs to be collective leadership over local systems and pathway development that crosses NHS and local authority boundaries at the level of 'place' ([Ham and Alderwick 2015](#)). A recent announcement by ministers of support for 'locality plans' for HIV should help with this ([Hansard 2017](#)).

In our view, directors of public health and lead clinicians for HIV are the people at local level around whom that leadership needs to coalesce. Directors of public health have the 'helicopter' view, expertise in partnership working and the ability to make connections across the health care, social care and public health systems. Lead HIV clinicians bring clinical and HIV-specific expertise and the ability to connect to the wider NHS. Directors of public health and lead clinicians are well placed to establish governance and processes to support work in partnership with others, including people living with HIV and the third sector. They need to work effectively together to ensure that the right leadership is in place and is able to take forward the development of future HIV services across both NHS and local authority areas of responsibility. They should identify individuals for the key roles to enable this.



### Recommendations for HIV services

- Directors of public health and lead HIV clinicians should work together to ensure effective system leadership to get all key stakeholders on board with a single, overarching plan for developing future services across the HIV pathway.
- The plan does not need to involve producing lengthy text. What is important is to establish: a shared understanding of how roles fit together to respond to changing need; governance across these roles; and relationships and ways of working that connect the currently fragmented system. In particular, the plan should:
  - tackle fragmentation and silos. For example, JSNAs and decisions about funding are needed for HIV support services, and joint commitment is needed to the long-term development of the workforce by not compartmentalising roles so that they become unattractive for recruitment or for training future professionals
  - focus on quality of life as well as clinical and public health priorities, including access to social support
  - ensure responsiveness and action on local changes – for example, in incidence and prevalence data, different groups' needs, and patterns of risk
  - meaningfully involve people living with HIV and user-led organisations – for example, in governance arrangements and in leading and contributing to work streams
  - align incentives for partnership. In the longer term, some form of pooling budgets and risk and reward sharing may help embed more integrated service models.

## Theme 2: Better alignment between HIV and wider health policy

The initial response to HIV, out of necessity, was an exceptional one, prompting the development of holistic specialist services, and separate funding. Because HIV care is becoming increasingly long term in nature, it needs closer co-ordination with the wider policy environment for health.

### Connecting with local strategies: health and wellbeing strategies and STPs

It is important that local HIV strategies not only engage the full range of commissioners, providers and service users but also connect with wider health and wellbeing strategies and STPs. This is vital if local HIV plans are to be coherent with the wider direction of travel, develop links and partnerships with other services similarly nested within these overall processes, and have profile and visibility.



There is a strong synergy between the principles that STPs and health and wellbeing strategies are working to and those that are needed for the future prevention of HIV and care for people living with HIV. For example, STPs and health and wellbeing strategies are focused on jointly identifying the best service models for each area's particular needs, rather than protecting existing configurations and will need to involve people and communities in shaping local changes.

However, this will not be easy. In practice, the success of health and wellbeing boards and the strategies they develop and oversee has been variable (Humphries and Galea 2013). Analysis by Evans *et al* (2013) of health and wellbeing strategies in areas of high HIV prevalence concluded that only 34 per cent included HIV in both their JSNA and resulting local strategy. Few STPs mention HIV services; they do not yet have detail behind this, and approaches to implementation will vary locally. Engaging with STPs and health and wellbeing boards will be important, but they will not offer blueprints for future HIV services; local system leadership across HIV services is still necessary for that. The levels of engagement that are possible will vary by area and will be low in some cases, creating a need for learning to be shared across the HIV sector to support those areas where progress is slower.

#### Recommendation for HIV services

- Local HIV plans should nest within health and wellbeing strategies and STP processes. Health and wellbeing board chairs (who are usually elected members) and the local STP leaders should facilitate this.

#### Better connections with policy on long-term conditions

While it is clear that people living long term with HIV will still require specialist care, it makes sense for HIV services and policy – both facing this challenge for the first time – to connect more strongly with the learning that other areas have already developed. Relationships between HIV and other clinical and care services – and, at a system level, engagement with commissioners – are currently at early stages of development and will need encouragement and support. There are interesting parallels between HIV and cancer services, where a new picture is similarly emerging of increasing numbers of people living for longer with long-term co-morbidities that need treatment alongside specialist cancer care, and services beginning to involve people more closely in managing their care (Macmillan Cancer Support undated; NHS England 2016b).



Policy on long-term conditions, and the tools and resources to support it, need to be developed for, and accessed more systematically by, HIV services and commissioners, with appropriate involvement of people living with HIV. For example, the ‘house of care’ approach to co-ordinating care for multiple long-term conditions around individual patients’ needs and preferences (Coulter *et al* 2013) offers a set of principles that are as relevant to HIV as to other long-term conditions. It will help enable co-ordination if the HIV sector adopts the same principles and vocabulary as other services that it needs to join up with. But HIV services need to lead the thinking about how frameworks developed in other services can be applied to HIV and how they may need to be adapted.

A better connection with broader policy on long-term conditions will help spread learning from the HIV sector too, such as how to successfully retain people in continuous care and how specialist and general practice roles should inter-relate in the future.

#### Recommendation for HIV services

- To support common approaches and enable learning from each other’s experience, HIV services should develop relationships with other services for people with long-term conditions (such as cancer services). They should also engage CCGs and commissioners of social care for older people (eg, care homes) in developing and implementing local HIV strategies.

### Theme 3: Planning for future models of care

Services will need to adapt to reflect the changing scale and patterns of need among people living with HIV, as well as changes in technology. Local areas will need to invest in developing approaches for their specific situation. The patient voice should be at the heart of this.

We suggest a two-stage approach to testing and developing future models of care.

#### Stage 1: Testing the future

Local areas need to be encouraged to develop and test new models of care for HIV. The vanguard programme (NHS England 2015) has been set up to explicitly support innovation and develop new models of care to drive implementation of the Forward View, and to ensure governance and oversight of it. There are



now 50 vanguards operating around the country, and they are beginning to make significant differences to care (Berwick 2016). They receive support to help evaluation, integration of commissioning, working more closely with patients and communities, and using new technology and redesigning workforce roles. NHS England will disseminate and scale up the features of models that receive positive evaluation. There is also a national vanguard for cancer services, to develop future care models in response to changing needs of people living with and beyond cancer.

HIV care has a similar need to explore future models of care, and we believe there is a strong case for some areas to trial HIV models as demonstrator sites, on a similar set of principles to the vanguard programme. Given that many areas are already starting to consider future models, there should be existing capability from pioneering services to respond to national encouragement and support.

Given our findings, the emphasis for these demonstrator sites should be on delivering comprehensive co-ordinated treatment and care across specialist HIV services, other specialist care, primary care and social care; and on testing shared care between consultant-led, primary care and community health services in the future.

There is good potential to encourage and test innovation for future HIV services if they are supported to unleash their creativity. New roles for service user groups and organisations, the use of digital technology for sharing medical information (including with patients), the rapid adoption of online ordering and reporting of self-administered tests, and video-call technology such as Skype or FaceTime for remote consultations (avoiding the need to travel to the clinic) are all starting to be used in HIV care in many areas of the country.

National stakeholders told us that there is also potential for developing new roles within HIV care. In various parts of the country, there are pioneering individuals among clinical nurse specialists developing their role in case management, and pharmacists developing expertise in HIV-related medicines and testing. As well as building on the work of these individuals for future care models, it is important that local services specifically consider how they can support the development of roles in the HIV workforce.





## Stage 2: Developing networks

Stronger and better aligned networks of care for people living with HIV are needed to co-ordinate the increasing complexity of co-morbidities and diverse needs. How exactly these networks are configured will depend on the scale and types of needs in different places in England. Examples include the following.

- **Vertical integration.** For many people with HIV, the current model of specialist HIV care, which is largely divorced from the rest of their experience of social and health care, will not be sufficient in the future. There needs to be a more coherent, holistic and integrated response to people's needs. Vertical integration (of commissioning, provision or both) is one way to achieve this, with specialist care, primary care, social care, third sector support and services (and, where relevant, prevention) more closely aligned around the patient.
- **Horizontal integration.** This may be something of particular relevance to large cities. For example, London currently has 30 HIV clinics with 18 providers each offering a different mix of care with differing resources. There is an increasing acceptance among clinicians that this configuration does not consistently meet the needs of people living with HIV in London. Joining up services for a critical mass of people with HIV with similar needs may make it easier to co-ordinate with other services and be more consistent in implementing good practice.
- **Hub and spoke.** A combination of vertical and horizontal models, hub and spoke may be particularly relevant where specialist services (which could be nurses and pharmacists as well as doctors) support a group of general practices, care homes or other services to provide appropriate care for people with HIV in the community. This may help address some of the worries that people living with HIV have about primary care and social care, and also address some of their concerns about problems with information sharing.

As local areas develop their HIV strategy, test future service models and develop networks, some are likely to need different organisational forms in order to realise and 'lock in' the benefits of integration for people living with HIV over time and enable services to work increasingly closely together. Here, we make recommendations for local systems; also recommendations for national bodies come later in this section.



#### Recommendations for HIV services

- HIV services need to test and develop future models for long-term HIV care, building on the work of pioneers who have already started developing shared care. These models will not be ‘one size fits all’, but must be locally appropriate, reflecting differing needs and circumstances.
- Service models are already lagging behind people’s needs so there is an urgency to the changes needed. Services and people living with HIV need to be open to future change and to partnerships, and local system leaders need to actively manage and lead the change process, ensuring that it is inclusive and clearly focused on better meeting people’s needs.

### Developing the role of national bodies in future HIV services

The diversity of different areas and population groups’ needs means that HIV services must be developed locally rather than top-down. The people we talked to during our research felt a lack of direction at national level, although there was little clear expression of what exactly was needed and certainly no consensus.

The message we have taken is that people want the national bodies (both statutory and representative) to help make the existing arrangements work better, not to rearrange responsibilities or reinvent top-down leadership. In this spirit, we set out below where we think national bodies and collective national leadership can play an essential role in improving HIV services and what they should do to develop services that meet people’s changing needs. Our recommendations are addressed to the body that has the lead for each area, but we would expect them to lead in an inclusive way, working with and engaging other stakeholders.

#### Recommendations for national bodies

- The Department of Health should:
  - update and strengthen the framework for sexual health improvement, reflecting the changing nature and challenge of preventing and living well with HIV in England in the 21st century, and providing an overall strategic direction for local HIV plans to reflect



- lead action to reduce and eradicate stigma associated with HIV and increase public understanding, ensuring engagement across government departments, at different levels, from government to individual services, and in health care together with NHS England
- ensure that there are clear expectations or indicators of progress for HIV prevention and care, with stronger arrangements for monitoring and accountability than at present
- ensure that the respective roles of the Department, NHS England and Public Health England are clear in relation to HIV, and that there is clarity about how local services are accountable to them. This includes ensuring clarity and facilitating constructive ways forward if confusion emerges over roles and responsibilities in the future, as it did with responsibility for providing and funding PrEP.
- NHS England should:
  - lead an inclusive process to decide the service models that it will commission in the future and how they fit with services commissioned by others. This will include:
    - supporting local development of models of shared care, by facilitating the dissemination of learning and good practice
    - developing, or supporting the development of, risk-stratified pathways of care – for example, focused on supporting a good quality of life for people with long-term viral suppression
    - working closely with Public Health England to deliver a PrEP implementation trial to better understand how it can be used most effectively, and plan for seamless implementation following a study of the trial
    - working with local government (ie, the LGA) to review and assess the scale and impact of commissioning strategies for HIV-specific and generic social support for people with HIV (including impacts on wellbeing, mental health, retention in care, and cost-benefit), publishing and reacting to the findings
    - keeping under review the status of HIV as a nationally commissioned specialised service, as commissioning capability and governance develop over time in STP footprints



- ensure that HIV services are engaged in the broader direction of travel for health services, and facilitate two-way learning. This will include:
  - exploring how policies and frameworks for long-term conditions (such as those for co-ordinating long-term care, care pathways, information-sharing systems and quality-of-life indicators) could be adapted for HIV services and could learn from the HIV sector's experience
  - facilitating the engagement of HIV services in the STP process, ensuring that learning is shared across HIV services on the range of experiences and opportunities identified through this, and engaging the HIV sector along with other specialised services on how to balance national and STP-level commissioning and service planning processes
- encourage and support the NHS to be the best it can in delivering high-quality, effective HIV treatment, care and prevention. This will include:
  - setting an ambition for the NHS workforce to ensure by 2025 that people experience care that is free of stigma towards HIV, and working with the Department of Health and other bodies to achieve this (the NHS needs to be an exemplar of zero stigma and demonstrate to other sections of society how to achieve this)
  - clarifying the role of specialised commissioners at area team level and how they will contribute to oversight and leadership of local services, and co-ordination of commissioning decisions
  - ensuring transparent and inclusive consideration of how savings for specialised commissioning budgets will be managed, particularly as ARV patents begin to expire.
- Public Health England should:
  - provide leadership to prioritise sexual health promotion and HIV prevention, building on the opportunities of increased testing and early indications of the impact of PrEP, so as to ensure combined approaches that focus on behavioural strategies as well as biomedical ones
  - continue to provide high-quality national and local information on HIV, and build on it by:
    - developing a wider range of HIV indicators in the Public Health Outcomes Framework for local areas to benchmark themselves against each other, in line with the Department of Health's lead in setting the overall monitoring accountability framework



- clarifying the relationship between Public Health England regional centres and local HIV services – providers as well as commissioners – so that there is greater clarity on how public health data leads to decisions on local action in response to it. A first priority for this should be tackling the wide variation in late diagnosis rates.
- Health Education England should:
  - engage with HIV services through its regional offices, and ensure that workforce implications, development needs and opportunities for innovation across the local system are identified and fully reflected in commissioning decisions.



## 6 Conclusion

We are already seeing a fundamental change in the needs of people living with HIV. This is a success story, reflecting both the effectiveness of HIV services in enabling people to stay healthy and advances in knowledge and treatments. HIV services now need to adapt to the very long-term nature of HIV care and co-ordinate with other health and care services as part of a holistic approach rather than work alongside them. But our case studies suggest that HIV services are not planning along the care ‘pathway’, and so are at risk of not keeping pace with changing needs.

Although we did not see that the fragmentation caused by the 2012 reforms has affected the clinical quality of HIV care that people experience, failing to adapt to changing needs will put quality of care at risk in the future. And at a time of financial pressures, the risk of taking unilateral commissioning decisions to achieve short-term cost savings needs to be considered carefully.

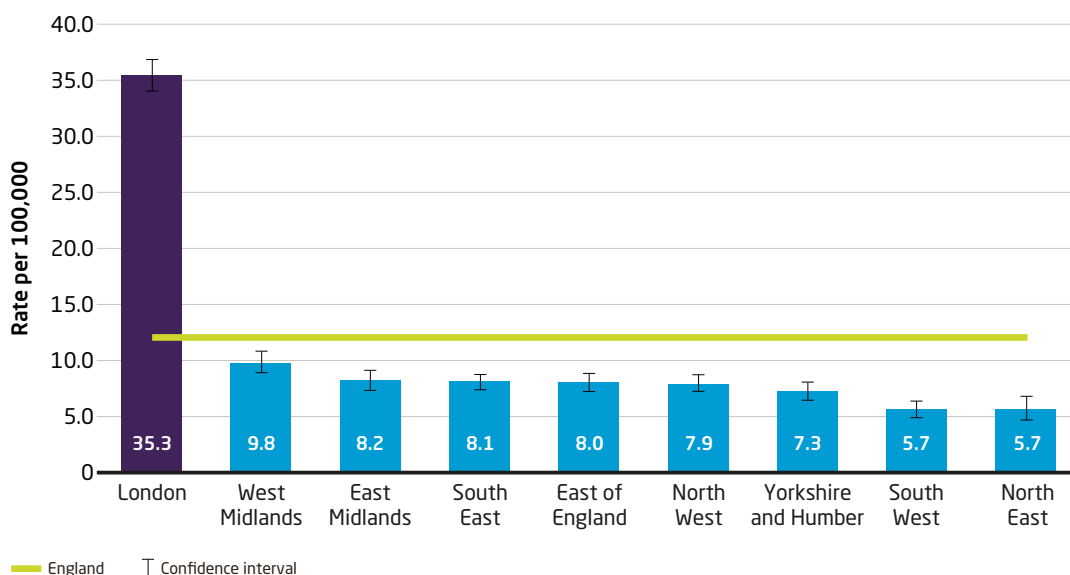
There are, however, actions that can be taken to avoid these risks. Models and frameworks for long-term care already exist; this is not a case of needing to design approaches from scratch. Adapting to the next stages of the evolution of HIV care needs leadership to make change happen and to ensure that the full range of specialists, secondary care, primary care and social care professionals – and, above all, people living with HIV – are engaged and on board. Again, models for system leadership already exist; some pioneering services are already engaged with it, and the overarching policy framework is encouraging integration across health and care services more generally. One of our case study areas was making progress through effective system leadership, joint governance and good-quality relationships. Progress should be entirely possible in other areas of the country too.

## Appendix A: HIV prevention and care in a complex system – the case of London

### HIV in London

Nearly half of all people receiving HIV care in the UK do so in London. Around one-quarter of England's new HIV cases are said to be diagnosed through one clinic in Dean Street and just over half of all UK new diagnoses among gay and bisexual men are made in London (Kirwan *et al* 2016). The overall new HIV diagnosis rate in London is more than three times higher than any other area of England (see Figure A1).

**Figure A1 New HIV diagnoses per 100,000 population aged 15 years or older by PHE centre of residence, 2015**



Source: Public Health England 2017



Some clinics in London have reported a fall in new diagnoses of HIV during 2016 ([Wilson 2017](#)). Public Health England is undertaking analysis to provide a better understanding of the factors that may be driving changes in HIV transmission (including earlier diagnosis and initiation of ART, and the use of PrEP), particularly among gay and bisexual men.

London is one of the world's most ethnically diverse cities. More than 300 languages are spoken there and, at the time of the 2011 census, over a third of its population were born outside the UK, of which just under a quarter were born outside of Europe ([Office for National Statistics 2013](#)). HIV incidence in London varies significantly by ethnic group, with the highest relative prevalence among black African communities ([Public Health England 2017](#)).

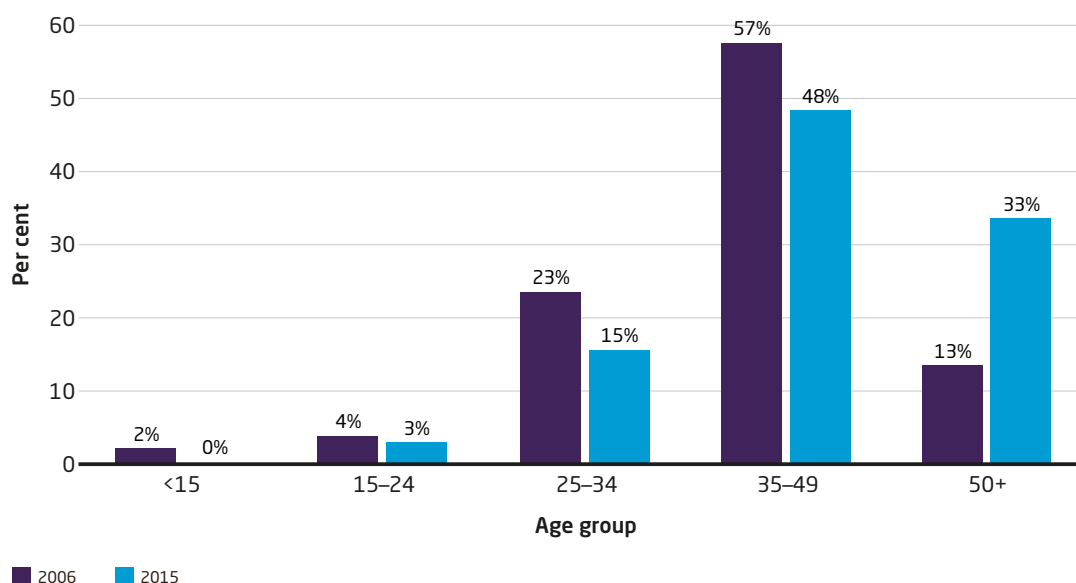
HIV incidence also varies significantly by place of residence ([Public Health England 2017](#)), with some inner-London boroughs (notably Lambeth and Southwark) having very high prevalence while a few boroughs have low prevalence (for example, Havering).

Overall, London's HIV late diagnosis rate is 34 per cent, which is below the England average of 40 per cent, but this remains too high and varies significantly by borough, from a high of 54 per cent in Croydon to a low of 20 per cent in Tower Hamlets ([Public Health England 2017](#)). Given the large number of people with HIV in London, this late diagnosis rate is particularly problematic due to poorer prognosis: people who are diagnosed late have a tenfold risk of mortality within one year of diagnosis compared with those diagnosed promptly ([Harris and Khatri 2015](#)). Furthermore, it also increases risks of onward transmission and the chance of epidemics while the virus remains untreated and therefore active.

There has been significant growth in the number of people diagnosed with HIV and accessing care in London in the past 15 years, rising from fewer than 24,000 in 2006 to almost 36,000 in 2015 ([Public Health England 2017](#)). Much of this growth is due to the increase in longevity associated with the introduction of ARV drugs. This will continue to change the nature of living with HIV and the service response to it. In London, as elsewhere, a generation of people living with HIV are 'greying', and



**Figure A2 Percentage of residents with diagnosed HIV and accessing care by age group, London, 2006 and 2015**



Source: Public Health England 2017

this presents new challenges for care. In 10 years, the proportion of people living with HIV in London aged 50 or over has leapt from 13 per cent to 33 per cent (see Figure A2). In absolute terms there has been an even bigger leap due to the overall rise in the HIV population; for every 10 people aged 50 or over living with HIV in London in 2006, there were 38 in 2015.

London has also seen a rise in other STIs such as gonorrhoea and syphilis (Public Health England 2016), particularly among gay and bisexual men. It is thought that some of this is related to changes in behaviour, particularly condomless sex and sero-adaptive matching of sexual partners. There is a palpable concern that sexual behaviours are changing fast and are not being influenced effectively by health promotion messages.



## HIV services in London

The way services in London are commissioned mirrors the national picture. But the complexities and fragmentation of that system are magnified and concentrated due to its scale, diversity and the density with which public services are commissioned, delivered and governed.

- NHS England commissions HIV treatment as a specialised service. London has a long history of HIV service reviews, but none of their recommendations have been fully implemented. Another review has started ([NHS England 2016d](#)), and is due to report in April 2017. One of its goals is to seek to understand the costs, utilisation and workforce implications of the current model of provision, including the inter-dependency of HIV and sexual health services.
- There are 18 providers, providing 30 specialist HIV clinics across London. A few of these are large, and there is a ‘tail’ of smaller providers.
- London’s local authorities jointly commission (through London Councils and the Association of Directors of Public Health) a pan-London HIV prevention programme. Hosted by Lambeth and known as the Do It London campaign, it has a particular focus on promoting HIV testing.
- London’s 33 local authorities also commission open-access sexual health services. Twenty-nine of the 33 are seeking to do this more collaboratively, and at lower cost, through a London Sexual Health Transformation Project ([London Councils undated b](#)), with a focus on online testing for HIV and other STIs. In addition, many sexual health services have been, or are being, recommissioned by local authorities as they seek to reshape services in the context of needing to reduce exposure of their shrinking public health budgets to sexual health services (which account for around 35 per cent of the public health budgets of London local authorities).



## The experience of people living with HIV in London

Our interviews with providers, commissioners, system leaders and those working in the voluntary and community sector, as well as our focus groups with people living with HIV, provided both reassurance and cause for concern about how people's experience of HIV care has been changing.

- As they are commissioned nationally, clinical services in London have (to date) mostly been insulated from changes in roles and responsibilities of other organisations. But many members of our focus groups were worried about the future of their specialist services and valued them highly.
- There was great concern about cutbacks to social, mental health and other support (including housing and welfare advice). These are the services that many people depend on to cope with HIV. This also included group and individual support for specific groups – for example, black Africans – both as community-based services and as in-reach to HIV clinics. We were told by commissioners and providers that these services were the ones that had been most vulnerable when budget cuts were needed.
- A strong message from our focus groups was that services do need to adapt over time, in particular to support the holistic care needs of people with HIV. Many recognised that their general care needs were changing and becoming more complex as they aged; the relationship between general practice and specialist care therefore needed to improve.
- People were worried about continuing stigma, and this was particularly so in relation to disclosure and confidentiality in the services where there was interest in closer interaction for more holistic care: general practice settings and, further into the future, social care and care homes.
- Some people were concerned about the behaviours of younger people currently at risk of HIV in London. In particular, there was a perception that because HIV is clinically manageable, it is no longer something to be concerned about in the way that it was in the past. Our focus groups were concerned that many people at risk had little conception of the constant daily struggles of living with HIV, despite the greater ability to control its clinical manifestations.



## Priority issues for London

The complex web of responsibilities, concurrent austerity, and the different timetable for NHS England's review of HIV services and London local authorities' sexual health transformation project have caused confusion and stress among London's HIV commissioners and providers. Although patient outcomes and experience appear to have held up to date, there is no guarantee they will continue to do so.

Major issues for London's system include the following.

1. A lack of ability to deal easily with issues that are clearly better dealt with across London's geography but are stymied by fragmented commissioning responsibilities and organisational boundaries. Four areas stand out.
  - a. **Prevention.** There is a pan-London approach to HIV prevention (the Do It London campaign), which has ensured high-visibility campaigns with consistent messaging. However, significant investment of time and effort has been needed to agree it across multiple partners. So far, resources have only been agreed for HIV testing but the campaign is now extending into broader STI and HIV prevention, which is a significant development. The role of Public Health England's London Centre in this is powerful in some regards, but weak in others; while it provides excellent epidemiological surveillance and can provide advice when asked for, it has no power to ensure that action is taken on HIV prevention across London in response to its data. Further, there is a tangible deficit in knowledge and policy on the social and behavioural aspects of prevention. This should not be taken to mean that HIV testing is not crucial, with higher rates needed to reduce onward transmission of HIV (Ogaz *et al* 2016), but a focus on testing needs to be complemented with targeted behavioural approaches too.
  - b. **Difficulties in co-ordination.** As an example of this we were told by multiple parties that London had an ambition to join the UN HIV Fast-track Cities initiative (IAPAC undated), which promotes sharing of expertise and learning across cities with similar challenges. While Paris and New York are members, London has struggled to identify who would have authority to sign the city up to it, due to split responsibilities.
  - c. **The alignment of NHS and local authority reviews.** Two significant major review programmes are ongoing in London: one by NHS England on the specialised commissioning of HIV treatment, and one by local authorities on



sexual health transformation. We heard that despite some attempts to align these they remain on different tracks and timetables. Both are due to report later in 2017, but there is no governance to ensure that they will dovetail.

- d. **The alignment of HIV provision and sexual health services recommissioning.** This is a complex issue. There are opportunities for improvement, including the introduction of a pan-London tariff and e-service through the London Sexual Health Transformation Project. However many providers are concerned that the re-tendering of sexual health services and the commissioning of future HIV services are not sufficiently co-ordinated ([Robertson et al 2017](#)). A particular concern is that the workforce – which currently works across both HIV and sexual health services – will no longer be affordable and may have limited roles, if the two services are split between separate providers. We also heard that to date, London's providers have acted as a de facto safety net for some HIV services on London's periphery, which had been destabilised by the separate commissioning of sexual health services. London's own sexual health services are due to be re-tendered in 2017, and it is far from clear how this will pan out.
2. The lack of a clear strategy across London (or at sub-level) on responding to the significant epidemiological change that has already happened, and will continue to do so. London's population with HIV is ageing fast; yet there is no sense of urgency about the need for models of care for people with HIV to change accordingly. Our recommendations in this area are all the more pressing for London. The lack of any significant role for London's CCGs is critical here, as they hold the key to how the NHS responds to long-term conditions.
3. Challenges in monitoring the effects of health and care reforms and austerity. The data (with the notable exception of Public Health England London's surveillance data) and information on how HIV care, patient experience and needs are changing in London are splintered, collected in different places and sometimes not collected at all. Due to inherent complexity and greater fragmentation, it is now hard for anyone to truly understand how the whole pathway of HIV care is performing and where the risks are.

Despite these challenges, we found no strong appetite from those we talked to for another major reorganisation or shifting of powers or responsibilities. No one we spoke to believed that the current system was ideal: it is too fragmented, lacks



coherent leadership and does not operate as an aligned system of care across the pathway from prevention to long-term care. But neither was there any clearly articulated alternative future outlined, despite recognition of the need to develop new models of commissioning and care that better reflect Londoners' needs.

## Opportunities for the future

The issues above need to be tackled urgently, but there are also significant opportunities for HIV services in London.

- The 2012 reforms (and, to some extent, the reaction to austerity) have led to more innovation. While this has not always been comfortable, particularly for providers, the local authority commissioning role for sexual health and for HIV prevention has resulted in faster innovation, notably the shift to online testing, which many may prefer. This is a 'big bang' approach to introducing change, and will require strong scrutiny and risk management as it is implemented. More broadly, local authorities have challenged the status quo and brought in a fresh approach to system oversight.
- The NHS England review has had a warmer welcome from London specialist providers than its predecessors. In particular, there is an acceptance of the need for more co-ordinated provision of services across London and a sense that London's clinicians wish to help lead this as a group, rather than simply as representatives of their organisations. In addition, there is now the opportunity for HIV services to dovetail with London's STP process (initial conversations are starting as this report goes to print). HIV is the epitome of a complex issue for which a place-based and cross-system (NHS and local authority) plan, such as an STP, should be a big part of the solution.
- The Do It London prevention campaign has been recommissioned with a stronger focus on HIV *and* wider sexual health ([London Councils undated a](#)). This is an important recognition of the complexity and inter-linkages of sexual behaviour in London.
- The London mayor's health inequalities policy is currently under development, and the new mayor made a commitment in his manifesto to work collaboratively with boroughs on HIV; he has also written to the London Assembly to reiterate his view that London needs to 'renew its focus on HIV', including



prevention ([Khan 2016](#)). In the absence of a strong appetite for any reorganisation of responsibilities, the London Health Board and the mayor's health inequalities strategy could play important roles in bringing together the pan-London leadership needed to develop future HIV services.

- London is doing relatively well on the UNAIDS 90:90:90 targets (although late diagnosis remains a problem). Early signs from some London clinics suggest that early diagnosis and initiation of ART, and also PrEP, could have a significant impact on reducing new cases of HIV. London looks set to continue being at the forefront of clinical excellence and now needs to ensure that HIV treatment is well integrated with holistic care and a focus on quality of life with HIV and co-morbidities.

London's services have been slow to respond to the changing needs of people living with HIV and the prevention strategies required to adapt to new sexual health behaviours such as chemsex. The 2012 reforms, which fragmented responsibilities and increased system complexity, alongside the onset of austerity, are key reasons for this.

In our view there is an opportunity in 2017 to bring together several strands of important work in London under one banner. There are many interlocking and important pieces of work and strategy that are all coming to a head in 2017, and they need to make sense as a whole.

Under whose auspices this happens is less important; what matters is that it does happen. The single most important issue facing London is the need to ensure clearer, stronger system leadership to drive forward progress in HIV and sexual health.



## Appendix B: Methodology

The research for this project took place between June 2016 and January 2017 when data collection finished. It comprised:

- a literature review
- analysis of literature and national data
- 34 interviews with key stakeholders
- five focus groups with people living with HIV (n=33 plus five interviews with individuals)
- 53 interviews in four case study areas, involving frontline staff and leaders in provider organisations, GPs, third sector organisations, commissioners, public health staff, elected members of councils
- interviews with three to five people from provider and commissioner organisations (oversight/leadership bodies in Scotland), in three additional areas. These were:
  - an area that contacted us, where an integrated HIV/sexual health service had been unsuccessful in its bid for the sexual health contract (n=5)
  - an area of middling HIV prevalence with trends clearly on track to become high prevalence (n=4)
  - Scotland (n=3)
- information about the project on The King's Fund website, which enabled people to submit comments to us
- workshops with stakeholders (n=45).

In addition to four members of The King's Fund staff, the research team involved a consultant physician specialising in HIV treatment and care, and three people living with HIV.





An advisory group of key stakeholders guided the research. It met three times and members included people living with HIV (UK-CAB), national statutory bodies (the Department of Health, NHS England, Public Health England), national professional and membership organisations (BHIVA, the Royal College of Physicians (RCP), RCGP, Medical Foundation for HIV and Sexual Health (MEDFASH), the Association of Directors of Adult Social Services (ADASS), LGA, Association of Directors of Public Health (ADPH), British Association for Sexual Health and HIV (BASHH) and English HIV and Sexual Health Commissioners Group), third sector organisations (National AIDS Trust, Positively UK, LGBT Foundation, Body and Soul, NAZ Project, African Health Policy Network and the Terrence Higgins Trust).

**Figure B1 Overview of approach and methods**

STAGES	i) How we got to where we are now	ii) Information collection and analysis	iii) Future scenarios
	<ul style="list-style-type: none"> <li>• Literature review</li> <li>• Data analysis</li> <li>• Expert advice</li> </ul>	<ul style="list-style-type: none"> <li>• Current strengths and weaknesses in serving people living with HIV</li> <li>• How emerging priorities in health policy impact on HIV</li> <li>• Capability to meet needs</li> <li>• Role of people living with HIV in driving developments</li> <li>• Current leading edge</li> </ul>	<ul style="list-style-type: none"> <li>• Defining alternative futures</li> <li>• Navigating towards the preferred and avoiding the worst</li> <li>• What needs to change to achieve this?</li> </ul>
METHODS	<ul style="list-style-type: none"> <li>• Literature review</li> <li>• Data analysis</li> <li>• Expert advice</li> </ul>	<ul style="list-style-type: none"> <li>• Literature and data review</li> <li>• Service user engagement</li> <li>• Key stakeholder engagement</li> <li>• Case studies</li> </ul>	<ul style="list-style-type: none"> <li>• Key stakeholder workshops</li> </ul>



## Literature and data

Our literature review focused on works published since 2000, across policy, guidance and research, on:

- the NHS (primary, secondary and tertiary care) and local authorities (including social care) as providers and also commissioners of HIV prevention, treatment and care services
- policy, legislation and reforms related to HIV
- HIV prevention, treatment and care in the future
- involvement and empowerment of people living with HIV, activists and voluntary and community organisations in HIV
- attitudes, knowledge and stigmatisation of HIV
- the HIV workforce and funding
- comparisons of HIV and HIV services in England with the situation in other countries.

The databases searched were the British Nursing Index, Cumulative Index to Nursing and Allied Health Literature, Embase, Health Business Elite, Health Management Information Consortium (HMIC), Department of Health Library and Information Services, The King's Fund Information and Knowledge Services, and the National Institute for Health and Care Excellence (NICE) Evidence Base and Social Care Online.

The data that we analysed came from Public Health England national data reports and regional sexual health profiles, plus data from within research articles.

## Stakeholder interviews

These interviews were used to help us understand the current situation in HIV services, and decide the focus for investigating risks and opportunities for the future. They focused on the effectiveness of current arrangements, risks and opportunities of emerging broader developments in health policy, what future HIV services should look like, and the role of national bodies.



## Focus groups

We undertook focus groups in the same areas as our case studies to help triangulate the findings, although the main purpose of the focus groups was to understand patient experience across the HIV pathway from prevention through to long-term care. We were interested in how different groups of people living with HIV may have had different (or similar) experiences.

We aimed to organise two focus groups in each case study site. We were able to recruit five focus groups in total, and we undertook a small number of individual interviews when not enough participants were available or able to take part in a focus group discussion – for example, in our rural case study area. Participants were all over the age of 18 and were recruited via HIV support organisations or NHS trusts.

Each focus group had a specific focus in terms of participants. These were:

- recently diagnosed adults (diagnosed within the past 18 months)
- black African women
- older people (aged 50 years and above)
- heterosexual men
- gay and bisexual men.

We developed a semi-structured topic guide to help with our focus groups. It covered care as it is now (eg, what part of your HIV care matters most to you?) and care as you would like it to be (eg, what would you like your role to be in your HIV services in the future?).

In addition, we were sent eight comments from individuals via The King's Fund website. They covered diverse issues and were analysed alongside focus groups where they self-identified as a person living with HIV (n=6) and alongside national stakeholders in other cases (n=2).



## Positive Voices survey

We developed three questions, in addition to those already in the survey. They collected additional information on the importance of: open-access HIV services; the role of general practice in HIV care and how joined up HIV services are with other services; and how appropriate HIV services are to people with different types of needs and characteristics. However, the length of time required to obtain ethical approval for the survey meant that we are unable to report any of the survey data in this publication.

## Case studies

We selected three case study areas to give a range of rural/urban, northern/southern spread, low/high HIV prevalence, and integrated/separate HIV and sexual health providers. Our visits to those areas were designed to look across the HIV 'pathway' of services for that area, from prevention to ongoing care. Their characteristics are summarised in a box in the main report (p 19).

The fourth case study area was London. We selected London because almost half of people accessing HIV care in the UK do so there (and so emerging trends are likely to become visible in London before other places); and also because it has a combination of cutting-edge services and a scale and complexity that is greater than HIV services anywhere else. We did not attempt to follow a single service in one or more of London's 33 boroughs, but treated the city as a system. We sampled from across it the various functions in HIV services (eg, commissioning, prevention, GP, etc) and asked as much as possible about London as a whole rather than only the individual local service.

Since London is such a major centre for HIV in England, we have set out our findings in more detail in appendix A.

In each case study area we used a semi-structured interview guide. It covered issues such as:

- changes in the past three to four years and what effects they have had
- how different local services work together



- implications of multiple commissioners, and the roles involved in managing them
- what range of services are provided and how suitable they are to different population groups
- how people living with HIV are involved in HIV services
- the biggest issues facing HIV services
- the greatest achievements of HIV services.

## Other interviews

We conducted some interviews in an area of ‘middling’ prevalence but on track to soon become high prevalence, in another part of the country, in order to make sure we did not only have views from solidly low, middling and high prevalence areas. We spoke to a provider and three commissioners there.

We were contacted by a provider about a negative experience of re-tendering sexual health services. To ensure that we heard a balanced range of views, we then spoke to the provider who won the tender, a third sector support service, the commissioner and the public health regional centre.

We spoke to three people in Scotland involved in HIV treatment, prevention and support, and system oversight. Our intention was to understand what they did differently to their English counterparts and why, in order to identify useful insights and learning points.

## Analysis

We recorded and transcribed interviews and analysed them using an online analysis tool (‘Dedoose’) and a coding framework that we developed.



## Workshops

As the project reached its conclusion we held two workshops with our advisory group plus a wider range of stakeholders (including people living with HIV). Their purpose was to test our findings and help inform the development of the findings as well as our key themes, and the structure and recommendations of our final report.

We used these workshops to seek insight into three questions for the future of the HIV system and policy in England:

- Given our findings about the current fragmented arrangements for HIV care, what would long-term HIV care integrated with care for co-morbidities look like and how could we get there?
- What should be the priorities for HIV prevention and how should we address them?
- What could national bodies do to enable local services to achieve these?

## References

Addicott R (2014). *Commissioning and contracting for integrated care*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/commissioning-contracting-integrated-care](http://www.kingsfund.org.uk/publications/commissioning-contracting-integrated-care) (accessed on 12 January 2017).

Advocates for Youth (undated). *Peer programs: looking at the evidence of effectiveness, a literature review*. Washington DC: Advocates for Youth. Available at: [www.advocatesforyouth.org/publications/publications-a-z/1856-peer-programs-looking-at-the-evidence-of-effectiveness-a-literature-review](http://www.advocatesforyouth.org/publications/publications-a-z/1856-peer-programs-looking-at-the-evidence-of-effectiveness-a-literature-review) (accessed on 8 February 2017).

Alderwick H, Dunn P, McKenna H, Walsh N, Ham C (2016). *Sustainability and transformation plans in the NHS: how are they being developed in practice?* London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/stps-in-the-nhs](http://www.kingsfund.org.uk/publications/stps-in-the-nhs) (accessed on 19 December 2016).

All-Party Parliamentary Group on HIV and AIDS (2016). *The HIV puzzle*. London: APPG on HIV and AIDS. Available at: [www.appghivaid.org.uk/reports/2016/puzzle.html](http://www.appghivaid.org.uk/reports/2016/puzzle.html) (accessed on 27 February 2017).

All-Party Parliamentary Group on Sexual and Reproductive Health in the UK (2015). *Breaking down the barriers*. London: APPG on Sexual and Reproductive Health in the UK. Available at: [www.fpa.org.uk/all-party-groups-sexual-health/appg-uk](http://www.fpa.org.uk/all-party-groups-sexual-health/appg-uk) (accessed on 4 January 2017).

Baird B, Charles A, Honeyman M, Maguire D, Das P (2016). *Understanding pressures in general practice*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/pressures-in-general-practice](http://www.kingsfund.org.uk/publications/pressures-in-general-practice) (accessed on 14 December 2016).

Berwick D (2016). 'How are the new care model vanguards working to improve outcomes?' The King's Fund website. Available at: [www.kingsfund.org.uk/blog/2016/11/how-are-new-care-model-vanguards-working-improve-outcomes](http://www.kingsfund.org.uk/blog/2016/11/how-are-new-care-model-vanguards-working-improve-outcomes) (accessed on 22 February 2017).

British HIV Association (BHIVA) (2011). *Standards for psychological support for adults living with HIV*. London: BHIVA. Available at: [www.bhiva.org/StandardsForPsychologicalSupport.aspx](http://www.bhiva.org/StandardsForPsychologicalSupport.aspx) (accessed on 22 February 2017).

Chau C, Kirwan P, Brown A, Gill N, Delpech V (2016). *HIV diagnoses, late diagnoses and numbers accessing treatment and care: 2016 report*. London: Public Health England. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/561098/HIV\\_diagnoses\\_late\\_diagnoses\\_and\\_numbers\\_accessing\\_treatment\\_and\\_care\\_NB181016v4.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/561098/HIV_diagnoses_late_diagnoses_and_numbers_accessing_treatment_and_care_NB181016v4.pdf) (accessed on 27 March 2017)



Coia N, Milne D, McAdams R, Morrison C, Winter A, Clutterbuck D, Carroll L, Baker G (2014). *HIV prevention: needs assessment of men who have sex with men*. Edinburgh: Scottish government. Available at: [www.gov.scot/Topics/Health/Services/Sexual-Health/HIVMSMNeeds](http://www.gov.scot/Topics/Health/Services/Sexual-Health/HIVMSMNeeds) (accessed on 1 December 2016).

Commission on the Future of Health and Social Care in England (2014). *A new settlement for health and social care: interim report*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/new-settlement-health-and-social-care-interim](http://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care-interim) (accessed on 2 August 2016).

Coulter A, Roberts S, Dixon A (2013). *Delivering better services for people with long-term conditions: building the house of care*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions](http://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions) (accessed on 4 January 2017).

Deeks S, Lewin S, Havlir D (2013). 'The end of AIDS: HIV infection as a chronic disease'. *The Lancet*, vol 382, no 9903, pp 1525–33.

Department for Education (2017). 'Schools to teach 21st century relationships and sex education'. Press release. GOV.UK website. Available at: [www.gov.uk/government/news/schools-to-teach-21st-century-relationships-and-sex-education](http://www.gov.uk/government/news/schools-to-teach-21st-century-relationships-and-sex-education) (accessed on 16 March 2017).

Department of Health (2015a). 'Long term health conditions'. GOV.UK website. Available at: [www.gov.uk/government/policies/long-term-health-conditions](http://www.gov.uk/government/policies/long-term-health-conditions) (accessed on 4 January 2017).

Department of Health (2015b). *Operational productivity and performance in English NHS acute hospitals: unwarranted variations*. London: Department of Health. Available at: [www.gov.uk/government/publications/productivity-in-nhs-hospitals](http://www.gov.uk/government/publications/productivity-in-nhs-hospitals) (accessed on 22 February 2017).

Department of Health (2013). *A framework for sexual health improvement in England*. London: Department of Health. Available at: [www.gov.uk/government/publications/a-framework-for-sexual-health-improvement-in-england](http://www.gov.uk/government/publications/a-framework-for-sexual-health-improvement-in-england) (accessed on 10 January 2017).

Department of Health (2011). *Joint strategic needs assessment and joint health and wellbeing strategies explained*. London: Department of Health. Available at: [www.gov.uk/government/publications/joint-strategic-needs-assessment-and-joint-health-and-wellbeing-strategies-explained](http://www.gov.uk/government/publications/joint-strategic-needs-assessment-and-joint-health-and-wellbeing-strategies-explained) (accessed on 2 August 2016).

Department of Health (2010). *Healthy lives, healthy people: our strategy for public health in England*. Cm 7985. London: The Stationery Office. Available at: [www.gov.uk/government/publications/healthy-lives-healthy-people-our-strategy-for-public-health-in-england](http://www.gov.uk/government/publications/healthy-lives-healthy-people-our-strategy-for-public-health-in-england) (accessed on 23 March 2017).

Ejbye J, Holman A (2016). *Making it happen: practical learning and tips from the five Realising the Value local partner sites*. London: Nesta. Available at: [www.nesta.org.uk/realising-value-programme-reports-tools-and-resources](http://www.nesta.org.uk/realising-value-programme-reports-tools-and-resources) (accessed on 3 January 2017).





Evans B, Moss J, Power L (2013). *Are health and wellbeing boards in higher HIV prevalence areas prioritising HIV prevention?* London: British HIV Association. Available at: [www.bhiva.org/documents/Conferences/2013Manchester/Presentations/Posters/Access-and-Service-Delivery/P2.pdf](http://www.bhiva.org/documents/Conferences/2013Manchester/Presentations/Posters/Access-and-Service-Delivery/P2.pdf) (accessed on 22 February 2017).

Fillingham D, Weir B (2014). *System leadership: lessons and learning from AQUA's Integrated Care Discovery Communities*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/system-leadership](http://www.kingsfund.org.uk/publications/system-leadership) (accessed on 22 February 2017).

Goodwin N, Dixon A, Poole T, Raleigh V (2011). *Improving the quality of care in general practice: report of an independent inquiry commissioned by The King's Fund*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/improving-quality-care-general-practice](http://www.kingsfund.org.uk/publications/improving-quality-care-general-practice) (accessed on 1 December 2016).

Granich R, Gilks C, Dye C, De Cock K, Williams B (2009). 'Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model'. *The Lancet*, vol 373, no 9657, pp 48–57.

Ham C, Alderwick H, McKenna H, Dunn P (2017). *Delivering sustainability and transformation plans: from ambitious proposals to credible plans*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/delivering-sustainability-and-transformation-plans](http://www.kingsfund.org.uk/publications/delivering-sustainability-and-transformation-plans) (accessed on 22 February 2017).

Ham C, Alderwick H (2015). *Place-based systems of care: a way forward for the NHS in England*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/place-based-systems-care](http://www.kingsfund.org.uk/publications/place-based-systems-care) (accessed on 19 December 2016).

Hansard (House of Commons Debates) (2017–18) 29 March 2017 vol 624. Available at: <https://hansard.parliament.uk/commons/2017-03-29> (accessed on 10 April 2017).

Harris J, Khatri R (2015). *Late diagnosis of HIV in the United Kingdom: an evidence review*. Liverpool: Liverpool John Moores University. Available at: [www.cph.org.uk/publications/](http://www.cph.org.uk/publications/) (accessed on 1 March 2017).

Health Committee (2016). *Public health post-2013*. HC 140 (2016–17). London: The Stationery Office. Available at: [www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2015/public-health-post-2013-inquiry-15-16/](http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2015/public-health-post-2013-inquiry-15-16/) (accessed on 23 January 2017).

Health Committee (2014). *Managing the care of people with long-term conditions*. HC 401 (2014–15). London: The Stationery Office. Available at: [www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/news/long-term-conditions-substantive/](http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/news/long-term-conditions-substantive/) (accessed on 1 December 2016).



Health Committee (2011). *Commissioning: third report of session 2010–11* HC 513 (2010–11). London: The Stationery Office. Available at: [www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/publications/?type=&session=3&sort=false&inquiry=802](http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/publications/?type=&session=3&sort=false&inquiry=802) (accessed on 2 August 2016).

Horn T, Sherwood J, Remien RH, Nash D, Auerbach J, for the Treatment Action Group and Foundation for AIDS Research HIV Prevention Continuum Working Group (2016). 'Towards an integrated primary and secondary HIV prevention continuum for the United States: a cyclical process model'. *Journal of the International AIDS Society*, vol 19, no 1. Available at: [www.jiasociety.org/index.php/jias/article/view/21263](http://www.jiasociety.org/index.php/jias/article/view/21263) (accessed on 18 December 2016).

Humphries R, Galea A (2013). *Health and wellbeing boards: one year on*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/health-and-wellbeing-boards-one-year-on](http://www.kingsfund.org.uk/publications/health-and-wellbeing-boards-one-year-on) (accessed on 22 February 2017).

Humphries R, Wenzel L (2015). *Options for integrated commissioning: beyond Barker*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/options-integrated-commissioning](http://www.kingsfund.org.uk/publications/options-integrated-commissioning) (accessed on 2 August 2016).

International Association of Providers of AIDS Care (IAPAC) (undated). *Fast-track cities*. IAPAC website. Available at: [www.iapac.org/cities/](http://www.iapac.org/cities/) (accessed on 22 February 2017).

Kall M, Shahmanesh M, Nardone A, Gilson R, Delpech V (2015). *Patient experience within NHS HIV specialist services: results from the Positive Voices pilot survey*. Available at: [www.ucl.ac.uk/voices/reports](http://www.ucl.ac.uk/voices/reports) (accessed on 23 January 2017).

Khan S (2016). Letter from Mayor of London to Dr Onkar Sahota, Chair of the Health Committee. 17 August 2016. Available at: [www.london.gov.uk/about-us/london-assembly/london-assembly-publications/hiv-prevention-london](http://www.london.gov.uk/about-us/london-assembly/london-assembly-publications/hiv-prevention-london) (accessed on 3 January 2017).

Kirwan P, Chau C, Brown A, Gill O, Delpech V (2016). *HIV in the UK – 2016 report*. London: Public Health England. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/574667/HIV\\_in\\_the\\_UK\\_2016.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/574667/HIV_in_the_UK_2016.pdf) (accessed on 13 December 2016).

Lazarus J, Safreed-Harmon K, Barton S, Costagliola D, Dedes N, del Amo Valero J, Gatell J, Baptista-Leite R, Mendão L, Porter K, Vella S, Rockstroh J (2016). 'Beyond viral suppression of HIV – the new quality of life frontier'. *BMC Medicine*, vol 14, no 94.

Local Government Association (LGA), Medical Foundation for HIV and Sexual Health (2015). *Sexual health commissioning in local government: case studies*. London: LGA. Available at: [www.medfash.org.uk/publications](http://www.medfash.org.uk/publications) (accessed on 2 August 2016).

London Councils (undated a). 'Do It London – winter 2017 phase'. London Councils website. Available at: [www.londoncouncils.gov.uk/node/31058](http://www.londoncouncils.gov.uk/node/31058) (accessed on 1 March 2017).



London Councils (undated b). 'London Sexual Health Transformation Project'. London Councils website. Available at: [www.londoncouncils.gov.uk/our-key-themes/health-and-adult-services/public-health/sexual-health-0/london-sexual-health](http://www.londoncouncils.gov.uk/our-key-themes/health-and-adult-services/public-health/sexual-health-0/london-sexual-health) (accessed on 1 March 2017).

MacLellan J, Shahmanesh M, Singh S, Morton J, Estcourt C, Asboe D (2017). *Shared care: how can we do it?* London: British HIV Association. Available at: [www.bhiva.org/shared-care.aspx](http://www.bhiva.org/shared-care.aspx) (accessed on 10 April 2017).

Macmillan Cancer Support (undated). Statistics fact sheet. Available at: [www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-story-is-changing/the-cancer-population.html#284337](http://www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-story-is-changing/the-cancer-population.html#284337) (accessed on 3 January 2017).

May M, Gompels M, Delpech V, Kholoud P, Post F, Dunn D, Palfreeman A, Gilson R, Gazzard B, Hill T, Walsh J, Fisher M, Orkin C, Ainsworth J, Bansi L, Phillips A, Johnson M, Nelson M, Anderson J, Sabin C (2011). 'Impact of late diagnosis and treatment on life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK CHIC) study'. *BMJ*, vol 2011, no 343, pp d6016.

McManus J, Harrison D (2016). 'Funding PrEP for HIV prevention'. *BMJ*, vol 354, no i3515. Available at: [www.bmj.com/content/354/bmj.i3515](http://www.bmj.com/content/354/bmj.i3515) (accessed on 2 August 2016).

Miners A, Llewellyn C, Cooper V, Youssef E, Pollard A, Lagarde M, Sabin C, Nixon E, Sachikonye M, Perry N, Fisher M (2016). 'A discrete choice experiment to assess people living with HIV's (PLWHIV's) preferences for GP or HIV clinic appointments'. *Sexually Transmitted Infections*, vol 2016, no 0, pp 1–7.

Mykhalovskiy E, Rosengarten M (2009). 'HIV/AIDS in its third decade: renewed critique in social and cultural analysis – an introduction'. *Social Theory and Health*, vol 7, no 3, pp 187–95.

National AIDS Trust (2017a). *Why we need HIV support services – a review of the evidence*. London: National AIDS Trust. Available at: [www.nat.org.uk/publications](http://www.nat.org.uk/publications) (accessed on 21 March 2017).

National AIDS Trust (2017b). *HIV support services – the state of the nations: executive summary*. London: National AIDS Trust. Available at: [www.nat.org.uk/publications](http://www.nat.org.uk/publications) (accessed on 21 March 2017)

National AIDS Trust (2016a). *HIV in the future NHS: what next for people living with HIV in England?*. London: National AIDS Trust. Available at: [www.nat.org.uk/publications](http://www.nat.org.uk/publications) (accessed on 22 February 2017).

National AIDS Trust (2016b). *Tackling HIV stigma: what works? Using the global evidence base to reduce the impact of HIV stigma*. London: National AIDS Trust. Available at: [www.nat.org.uk/publications](http://www.nat.org.uk/publications) (accessed on 22 February 2017).



National AIDS Trust (2015). *HIV prevention in England's high prevalence local authorities: 2013/14 and 2014/15*. London: National AIDS Trust. Available at: [www.nat.org.uk/publications](http://www.nat.org.uk/publications) (accessed on 2 August 2016).

National AIDS Trust (2014). *HIV: public attitudes and knowledge, 2014*. London: National Aids Trust. Available at: [www.nat.org.uk/publication/hivpublic-knowledge-and-attitudes-2014](http://www.nat.org.uk/publication/hivpublic-knowledge-and-attitudes-2014) (accessed on 10 April 2017).

Naylor C (2011). 'Will the government's new mental health strategy succeed?' Blog. The King's Fund website. Available at: [www.kingsfund.org.uk/blog/2011/02/will-governments-new-mental-health-strategy-succeed](http://www.kingsfund.org.uk/blog/2011/02/will-governments-new-mental-health-strategy-succeed) (accessed on 1 December 2016).

NHS England (2016a). 'NHS England announces major extension of national HIV prevention programme with Public Health England and funding for ten new specialised treatments'. NHS England website. Available at: [www.england.nhs.uk/2016/12/hiv-prevention-programme/](http://www.england.nhs.uk/2016/12/hiv-prevention-programme/) (accessed on 16 March 2017).

NHS England (2016b). *Achieving world class cancer outcomes: taking the strategy forward*. London: NHS England. Available at: [www.england.nhs.uk/cancer/strategy/](http://www.england.nhs.uk/cancer/strategy/) (accessed on 27 March 2017).

NHS England (2016c). *Engaging local people: a guide for local areas developing sustainability and transformation plans*. London: NHS England. Available at: [www.england.nhs.uk/stps/support/#localstp](http://www.england.nhs.uk/stps/support/#localstp) (accessed on 8 February 2017).

NHS England (2016d). *Improving value for patients from specialised care: commissioning intentions 2016/2017 for prescribed specialised services*. London: NHS England. Available at: [www.england.nhs.uk/commissioning/spec-services/key-docs/](http://www.england.nhs.uk/commissioning/spec-services/key-docs/) (accessed on 3 January 2017).

NHS England (2016e). 'Long term conditions, older people and end of life care'. NHS England website. Available at: [www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/](http://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/) (accessed on 27 March 2017).

NHS England (2015). *The Forward View into action: new care models: support for the vanguards*. London: NHS England. Available at: [www.england.nhs.uk/ourwork/new-care-models/vanguards/support/](http://www.england.nhs.uk/ourwork/new-care-models/vanguards/support/) (accessed on 23 January 2017).

NHS England (2013). *Service specifications for specialised HIV services (adult, children)*. London: NHS England. Available at: [www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f03/](http://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f03/) (accessed on 2 August 2016).

NHS England (undated). 'Integrated care pioneers'. London: NHS England. Available at: [www.england.nhs.uk/integrated-care-pioneers/](http://www.england.nhs.uk/integrated-care-pioneers/) (accessed on 3 January 2017).



NHS England, Care Quality Commission, Health Education England, Monitor, NHS Trust Development Authority, Public Health England (2014). *NHS five year forward view* [online]. London: NHS England. Available at: [www.england.nhs.uk/ourwork/futurenhs/](http://www.england.nhs.uk/ourwork/futurenhs/) (accessed on 23 January 2017).

NHS England, NHS Improvement, Care Quality Commission, Health Education England, National Institute for Health and Care Excellence (NICE) (2015). *Delivering the Forward View: NHS planning guidance 2016/17 – 2020/21*. London: NHS England. Available at: [www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/](http://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/) (accessed on 2 August 2016).

NICE (2016a). *HIV testing: increasing uptake among people who may have undiagnosed HIV*. London: NICE. Available at: [www.nice.org.uk/guidance/ng60](http://www.nice.org.uk/guidance/ng60) (accessed on 18 December 2016).

NICE (2016b). *Multimorbidity: clinical assessment and management*. NICE guideline NG56. London: NICE. Available at: [www.nice.org.uk/guidance/ng56](http://www.nice.org.uk/guidance/ng56) (accessed on 20 December 2016).

Office for National Statistics (2013). '2011 census: local characteristics on ethnicity, identity, language and religion for output areas in England and Wales'. Available at: [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/2011censuslocalcharacteristicsone ethnicityidentitylanguageandreligionforoutputareasinenglandandwales](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/2011censuslocalcharacteristicsone ethnicityidentitylanguageandreligionforoutputareasinenglandandwales) (accessed on 3 January 2017).

Ogaz D, Furegato M, Connor N, Gill O (2016). *HIV testing in England: 2016 report*. London: Public Health England. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/573596/HIV\\_testing\\_in\\_England\\_2016\\_Report\\_FinalNB301116.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/573596/HIV_testing_in_England_2016_Report_FinalNB301116.pdf) (accessed on 14 December 2016).

Phillips A (2015). *HIV in MSM in the UK: prevention effects of ART in perspective*. Presentation at the 21st Annual Conference of BHIVA, 21–24 April 2015, Brighton, UK. Available at: [www.bhiva.org/Presentations150422.aspx](http://www.bhiva.org/Presentations150422.aspx) (accessed on 4 January 2017).

Public Health England (2017). *Annual epidemiological spotlight on HIV in London: 2015 data*. London: Public Health England. Available at: [www.gov.uk/government/publications/hiv-london-annual-data-spotlight](http://www.gov.uk/government/publications/hiv-london-annual-data-spotlight) (accessed on 1 March 2017).

Public Health England (2016). 'Sexually transmitted infections (STIs): annual data tables'. Public Health England website. Available at: [www.gov.uk/government/statistics/sexually-transmitted-infections-stis-annual-data-tables](http://www.gov.uk/government/statistics/sexually-transmitted-infections-stis-annual-data-tables) (accessed on 1 December 2016).

Public Health England (2014a). *Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV*. London: Public Health England. Available at: [www.gov.uk/government/publications/commissioning-sexual-health-reproductive-health-and-hiv-services](http://www.gov.uk/government/publications/commissioning-sexual-health-reproductive-health-and-hiv-services) (accessed on 19 December 2016).



Public Health England (2014b). *Promoting the health and wellbeing of gay, bisexual and other men who have sex with men: initial findings*. London: Public Health England. Available at: [www.gov.uk/government/publications/promoting-the-health-and-wellbeing-of-gay-bisexual-and-other-men-who-have-sex-with-men](http://www.gov.uk/government/publications/promoting-the-health-and-wellbeing-of-gay-bisexual-and-other-men-who-have-sex-with-men) (accessed on 20 December 2016).

Punyacharoensin N, Edmunds WJ, De Angelis D, Delpech V, Hart G, Elford J, Brown A, Gill N, White R (2015). 'Modelling the HIV epidemic among MSM in the United Kingdom: quantifying the contributions to HIV transmission to better inform prevention initiatives'. *AIDS*, vol 29, no 3, pp 339–49.

Robertson R, Wenzel L, Thompson J, Charles A (2017). *Understanding NHS financial pressures: how are they affecting patient care?* London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/understanding-nhs-financial-pressure](http://www.kingsfund.org.uk/publications/understanding-nhs-financial-pressure) (accessed on 6 April 2017).

Royal College of General Practitioners (2016). 'HIV, sexual health and reproductive health project announced by RCGP'. London: RCGP website. Available at: [www.rcgp.org.uk/news/2016/august/hiv-sexual-and-reproductive-health-project-announced-by-rcgp.aspx](http://www.rcgp.org.uk/news/2016/august/hiv-sexual-and-reproductive-health-project-announced-by-rcgp.aspx) (accessed on 8 February 2017).

Scottish Government (2015). *Sexual health and blood borne virus framework 2015–2020 update*. Edinburgh: Scottish Government. Available at: [www.gov.scot/Publications/2015/09/5740/](http://www.gov.scot/Publications/2015/09/5740/) (accessed on 23 January 2017).

Smith J, Holder H, Edwards N, Maybin J, Parker H, Rosen R, Walsh N (2013). *Securing the future of general practice: new models of primary care*. London: Nuffield Trust. Available at: [www.nuffieldtrust.org.uk/publications/securing-future-general-practice](http://www.nuffieldtrust.org.uk/publications/securing-future-general-practice) (accessed on 1 December 2016).

Sonnenberg P, Soazig C, Beddows S, Field N, Soldan K, Tanton C, Mercer C, Coelho da Silva F, Alexander S, Copas A, Phelps A, Erens B, Prah P, Macdowall W, Wellings K, Ison C, Johnson A (2013). 'Prevalence, risk factors, and uptake of interventions for sexually transmitted infections in Britain: findings from the National Surveys of Sexual Attitudes and Lifestyles (Natsal)'. *The Lancet*, vol 382, no 9907, pp 1795–806.

Stigma survey UK (2015). *Stigma survey UK 2015*. Available at: [www.stigmaindexuk.org/research-findings/](http://www.stigmaindexuk.org/research-findings/) (accessed on 23 January 2017).

Stuart A (2013). *Double Jeopardy Project: a final report on the Trust for London funded Double Jeopardy Project*. London: MBARC. Available at: [www.trustforlondon.org.uk/research/publication/being-more-inclusive-of-lgbti-asylum-seekers-refugees-and-migrants/](http://www.trustforlondon.org.uk/research/publication/being-more-inclusive-of-lgbti-asylum-seekers-refugees-and-migrants/) (accessed on 23 March 2017).

Terrence Higgins Trust (2017). *Uncharted territory*. London: Terrence Higgins Trust. Available at: [www.tht.org.uk/myhiv/Staying-healthy/Health-Wealth-and-Happiness](http://www.tht.org.uk/myhiv/Staying-healthy/Health-Wealth-and-Happiness) (accessed on 5 April 2017).





Timmins N (2012). *Never again? The story of the Health and Social Care Act 2012*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/never-again](http://www.kingsfund.org.uk/publications/never-again) (accessed on 22 February 2017).

UNAIDS (2016). *Prevention gap report*. Geneva: UNAIDS. Available at: [www.unaids.org/en/resources/documents/2016/prevention-gap](http://www.unaids.org/en/resources/documents/2016/prevention-gap) (accessed 10 April 2017).

West M, Eckert R, Stewart K, Pasmore B (2014). *Developing collective leadership for healthcare*. London: The King's Fund. Available at: [www.kingsfund.org.uk/publications/developing-collective-leadership-health-care](http://www.kingsfund.org.uk/publications/developing-collective-leadership-health-care) (accessed on 22 February 2017).

Wilson C (2017). 'Massive drop in London HIV rates may be due to internet drugs'. *New Scientist*. Available at: [www.newscientist.com/article/2117426-massive-drop-in-london-hiv-rates-may-be-due-to-internet-drugs/](http://www.newscientist.com/article/2117426-massive-drop-in-london-hiv-rates-may-be-due-to-internet-drugs/) (accessed on 1 December 2016).

Yin Z, Kall M, Skingsley A, Delpech V (2015). 'Over half of people in HIV care in the UK by 2028 will be aged 50 years or above'. Presentation at the 15th European AIDS Conference, 21–24 October 2015, Barcelona, Spain. Available at: [www.ucl.ac.uk/voices/reports](http://www.ucl.ac.uk/voices/reports) (accessed on 23 January 2017).



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Before joining the Fund, Alex worked at the Care Quality Commission (CQC), where he led development of the framework and approach for inspecting and rating hospitals, and before that at the Healthcare Commission, where he introduced risk-based regulation in the independent sector. Alex also led the CQC's work with the Department of Health on the policy and legal framework for quality regulation, working with the Department and other national bodies to agree roles and responsibilities for responding to serious concerns.

Before working in quality regulation, Alex worked in management in two NHS trusts. He has also worked at the Department of Health and at the World Health Organization (WHO) Regional Office for Europe in Copenhagen.

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Before joining The King's Fund, David worked at the Department of Health as deputy director for health inequalities. He managed the Labour government's Public Service Agreement (PSA) target on health inequalities and the independent Marmot Review of inequalities in health. While at the Department he worked on many policy areas – including diabetes, long-term conditions, dental health, waiting times, the pharmaceuticals industry, childhood obesity, and choice and competition – as an economic and strategy adviser. He has also worked at Guy's Hospital, King's College London and the Centre for Health Economics in York, where his focus was on the economics of public health and behaviours and incentives.

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From 2013–16 she was seconded part-time to Public Health England and currently chairs its External Advisory Group for HIV and Sexual/Reproductive Health and the tripartite partnership board for Sexual Assault Referral Centres. She represents London clinicians on the NHS England Clinical Reference Group for HIV. Jane is Chair of the National AIDS Trust and a past Chair of the British HIV Association. She was appointed CBE in 2015.

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Joni has a particular interest in incentives and behavioural outcomes in health care settings. Before joining the Fund in 2013, she worked at the Royal College of Physicians, focusing on the impact of the NHS reforms, developing new models of urgent and emergency care services, and leading the college's public health work.

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**The King's Fund** is an independent charity working to improve health and care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible care is available to all.

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People with HIV are now living into older age and developing other conditions linked to ageing. Are HIV services adapting to meet changing needs? And how have the 2012 health and care reforms affected HIV services?

*The future of HIV services in England* makes recommendations to national and local stakeholders on how best to develop HIV services over the next 5–10 years. Through a review of the literature and data, stakeholder interviews and four case studies, it looks at how HIV services are faring in the context of changing needs, changing roles and responsibilities and a changing policy environment.

Our research found that:

- the 2012 reforms have resulted in a fragmented health and care system that has made co-ordination of HIV services more difficult and while this has not yet affected the clinical quality of care, it could do so in future
- good HIV care is no longer just about virus suppression; it should also promote a good quality of life, freedom from stigma, and people managing their own care
- unilateral commissioning decisions and financial pressures are putting at risk some vital non-clinical services such as HIV support organisations and HIV prevention activities
- national bodies have become too 'hands-off'; while there is no appetite for further rearrangement of responsibilities or top-down changes, there is widespread support for making existing arrangements work better.

HIV services should align with broader efforts locally and nationally to improve co-ordination and deliver integrated, person-centred and place-based care. Locally, directors of public health and lead HIV clinicians should work together to get all key stakeholders (including people with HIV) on board with a single, overarching plan to develop HIV services across the pathway. Care models should be developed locally to reflect differing needs and be nested within health and wellbeing strategies and sustainability and transformation plans. National bodies should set the overall direction for HIV services, ensuring accountability, and supporting the development of new care models and good practice.

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